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EDUCATION AND REHABILITATION OF PERSONS WITH HEAD INJURIES

HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

EXAMINING THE TRAGEDIES SURROUNDING HEAD INJURIES AND FOCUSING ON EDUCATION AND REHABILITATION OF PERSONS WITH SUCH INJURIES

APRIL 12, 1988

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CONTENTS

STATEMENTS

APRIL 12, 1988

	Page
Bentsen, Hon. Lloyd, a U.S. Senator from the State of Texas, prepared statement	37
Brady, James, Press Secretary, President Reagan, Honorary National Head Injury Foundation Chairperson, and Sarah Brady, Honorary National Head Injury Foundation Chairperson	16
Prepared statement of James and Sarah Brady	20
Harkin, Hon. Tom, a U.S. Senator from the State of Iowa, prepared statement	2
King, Albert I., Ph.D., Carr Professor of Engineering, Wayne State University, prepared statement	150
Marshall, Larry, M.D., Division of Neurosurgery, University of California, San Diego, CA	27
Prepared statement	30
Mossington, Helen L., prepared statement	151
Mulvey, Cynthia, East Haven, CT; Gerald Bush, Ph.D., NHIF chairman of the board (outgoing), Heller School, Brandeis University, Waltham, MA, and Charles Haynes, NHIF chairman of the board (incoming), Houston, TX	38
Prepared statements of:	
Ms. Mulvey	40
Dr. Bush	49
Mr. Haynes	64
Simon, Hon. Paul, a U.S. Senator from the State of Illinois, prepared statement (with an attachment)	5
Smith, Renae, prepared statement	154
Stern, Marc, prepared statement	149
Verduyn, Walter, M.D., Covenant Medical Center, Waterloo, IA, and Howard Katz, M.D., chief of head injury service, Mississippi Methodist Rehabilitation Center, Jacksonville, MI	72
Prepared statements of:	
Dr. Verduyn	76
Dr. Katz	93
Weicker, Hon. Lowell P., Jr., a U.S. Senator from the State of Connecticut, prepared statement	13
Will, Madeleine, C., Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education, prepared statement	141

EDUCATION AND REHABILITATION OF PERSONS WITH HEAD INJURIES

TUESDAY, APRIL 12, 1988

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED
OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:15 p.m., in room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Metzenbaum, Weicker, Stafford, and Cochran.

OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. The Subcommittee on the Handicapped will come to order. The Subcommittee on the Handicapped is very proud to hold this hearing, the first time in history that a Senate hearing has focused exclusively on the education and rehabilitation of persons with head injuries.

While many people have played a key role in bringing about this hearing, I especially want to recognize two individuals. I first want to recognize my esteemed colleague, Senator Lowell Weicker, who preceded me as chairman of this subcommittee, and who has given me sound advice and counsel and guidance as I took over the chairmanship just last year.

We have a close personal friendship and working relationship. He has been a great champion of all persons with disabilities for many, many years, and I just want to thank you, Lowell, and say it has been a pleasure to work with you and have your support in this effort.

Secondly, I would recognize Senator Metzenbaum, who will be here shortly, who wrote me a letter last year asking that we have a hearing focused exclusively on this topic. So he is really responsible for getting the ball rolling on this hearing.

I have been consistently impressed with Senator Metzenbaum's sensitivity and understanding of the problems faced by persons with disabilities. He has been truly a courageous champion, not just of people with disabilities, but the elderly, women, minorities. It is a privilege to have you here today with us, Howard, and I thank you for getting that letter to me last year and getting the ball rolling on this.

[The prepared statements of Senators Tom Harkin, and Paul Simon, with an attachment follow:]

OPENING STATEMENT
SENATOR TOM HARKIN

THE EDUCATION AND REHABILITATION OF PERSONS WITH HEAD INJURIES

April 12, 1988

This hearing will come to order. The Subcommittee on the Handicapped is proud to hold this hearing, the first time in history a Senate hearing has focused exclusively on the education and rehabilitation of persons with head injuries.

While many people have played a role in bringing about this hearing, I especially want to recognize my esteemed colleague, Howard Metzenbaum, who wrote me a letter last year requesting this hearing - - he really is responsible for getting the ball rolling.

I have been consistently impressed by the Senator from Ohio's great sensitivity and understanding of the problems faced by persons with disabilities. As Chairman of the Subcommittee on the Handicapped, when I need advice or support, I turn to Senator Metzenbaum. He doesn't blow his own horn, so I'll do it for him. He has truly been a courageous champion, not just of people with disabilities, but of the elderly, of women, and of minorities. And, Howard, it is a privilege to work with you.

Each year, 500,000 to 700,000 people are hospitalized after suffering a head injury. Today, because of improvements in our acute health care system, most will survive - - many more than would have survived even a decade ago.

Yet, for those who survive, as the National Head Injury Foundation has stated, "life is never the same." In a silent epidemic few have noted, we have created a whole new class of citizens with disabilities.

Life is a precious commodity -- but it is not enough to save a person's life, a person who is now mentally, physically, and/or socially disabled, and say smugly "we have done all we can do." I reject that notion -- and I think the hearing today will show, we <u>can</u> do more.

Of the hundreds of thousands of Americans who sustain significant head injuries, only five percent will get all the

help they need. Yes, appropriate care can be expensive. But the cost of doing nothing is far greater.

All of us in society bear the cost of emotional stress and family strife caused by head injuries.

And all of us, to put it in purely economic terms -- though it is far more than an economic problem -- bear the cost of wasted lives and wasted opportunities. The lifetime cost in lost potential income, plus expenses, for a brain-damaged 20-year old has been estimated at $4 million. One study has shown that, if only 40% of those treated return to gainful employment, the savings in Social Security benefits and other forms of public assistance would more than pay the cost of rehabilitation.

So, what can we do? I believe we must provide appropriate ongoing education and rehabilitation that will enable survivors to become as independent, productive, and integrated into the community as possible. But, based on the testimony we will hear today, it appears that, as a Nation, we have a long way to go before we can say that we have met these goals.

A brain injury can affect many life functions - - physical, intellectual, and emotional. Young head injury survivors may return to school to find that they have lost some of their basic academic skills and thinking processes, and that they have problems socializing with their peers. Working adults may find that memory deficits, lack of concentration, or slowness of thinking make it difficult for them to do their old jobs.

Because brain injury can affect so many life functions, appropriate treatment and rehabilitation must involve almost every medical and rehabilitation discipline that exists - - physicians, psychiatrists, psychologists, nurses, physical therapists, vocational counselors, special educators, to name a few. And in order to provide appropriate services to head injury survivors, these professionals must have the special training to address the special needs of this population.

Traditional strategies used for educating and rehabilitating persons with disabilities often aren't effective for brain injury survivors. Unfortunately, as I know some of you will testify today, our service delivery systems for head injury survivors are too often fragmented, and few survivors receive adequate long-term support.

Traumatic brain injury doesn't only affect its victim; it takes a heavy toll on families as well. Many times, a working

parent or spouse is forced to quit work in order to care for an injured loved one at home - - there simply aren't any alternatives. But the financial burdens are only the beginning. Adjusting to the changes in their family member's behavior; coping with feelings of guilt or depression; and battling the confusing maze of service delivery systems - - these all place families under tremendous stress. And so families need to be considered in the rehabilitation picture as well.

Well, as that great baseball philosopher, Yogi Berra, once said, "If you don't know where you're going, you might end up someplace else." Well, if we don't want to end up somewhere else, we need to examine a better direction for policies to help head-injury victims and their families. We need to have far better coordination to eliminate duplicative efforts and to ensure that we are moving forward as best as possible in providing more accessible and more affordable treatments.

And finally, we need to commit the resources to get results. Saving a person from death is only half the battle -- the time has come for our nation to finish the battle and win the war.

I am especially pleased that we are holding this hearing during the annual meeting of the National Head Injury Foundation, an organization that has probably done more than any other to bring the concerns of the survivors of head injuries and their families to the attention of the public. I would especially like to recognize Marilyn Price Spivack, the President and Co-Founder of the National Head Injury Foundation. I would also like to recognize a number of fellow Iowans who may be here today - - Dr. William McMordie, Karen Johnson, Kathy Herring, Mr. and Mrs. Pat Steele, Linda Linder, Jerry and Jo Anne Kramer, and Mrs. William Stonebrook.

April 12, 1988
Subcommittee on the Handicapped
Education and Rehabilitation of Head Injury Victims
Statement By Senator Paul Simon

I want to thank Senator Harkin and my colleagues on the Committee for conducting this important hearing. The information we gather from this hearing today will help educate the members of this committee on the hopes and needs of those who have suffered traumatic head injuries.

This type of injury may not always be visible, but the damage can be measured by the intellectual, emotional, social, and vocational changes in a person. The statistics are staggering, and cannot be repeated too often: One million children suffer head injuries annually, and 400,000 to 500,000 Americans are admitted to hospitals yearly as a result of traumatic brain injuries. The average rate of serious injuries, that often disable our young people for life, is between 200 and 400 per 100,000.

Medical costs are estimated at $4 billion per year, which does not account for the losses in productivity, potential wages, or impact on our social and human services systems. Most victims of this type of injury are between the ages of 15 and 25. Head injuries kill more Americans under the age of 34 than all other diseases combined.

We simply must learn more about what we can do to help these young people take their proper place as contributing members in our society, and about what we can do to prevent the bankrupting of families and the devastation of their resources as a consequence of the enormous and ongoing costs of care for individuals with head injuries.

During a meeting with members of the Illinois Head Injury Association in 1986, I asked Dr. Barry Rath, the Clinical Director of the Schwab Rehabilitation Center in Chicago, for his recommendations in regard to the issue of traumatic brain injury. In his written response, he stressed five areas that should be considered: prevention, research and training, rehabilitation and training, life care, and awareness/advocacy. I would like to have his letter made a part of this hearing record. I would certainly urge that the Committee look carefully at the areas he mentioned.

Studies have shown that traumatic head injuries will continue at an alarming rate unless we are willing to take steps to change this situation. The combined efforts of the Congress, medical institutions, and the informed support of the American people will be necessary to lead us to new possibilities concerning the reduction of traumatic brain injuries and more appropriate care and treatment for those whose lives have been so severely affected. I look forward to working with the members of this Subcommittee to reach these goals.

SCHWAB [redacted] PHASE FOUR

PHASE I PHASE II PHASE III PHASE IV

A Comprehensive Four Phased Head Trauma Program from Coma to Community Re-entry

April 23, 1986

The Honorable Paul Simon
Senator for Illinois
SD 462 Dirkson Building
Washington, D.C. 20510

Dear Senator Simon:

Pursuant to our meeting on April 18, 1986 when you generously shared your time with our group from the Illinois Head Injury Association (IHIA), our state chapter of the National Head Injury Foundation (NHIF), I am submitting to you the "homework assignment" you gave me. You will recall, you asked me if I were Senator what five things would I do:

The Problem: NHIF has called the problem of traumatic brain injuries "The Silent Epidemic". Head injury has taken more American lives than all America's wars since the birth of our country and is the leading cause of death for persons under age 44. Serious head injuries kill more Americans under age 34 than all other diseases combined. Serious head injury accounts for 500,000 hospitalizations each year with many requiring extended service and leaving permanent disability. The cost of these hospitalizations alone is more than half-a-billion dollars not to mention the loss of 4.1 million years of productive pre-retirement life lost each year. Tragically, we spend only approximately 4 million dollars on head injury research annually. Tragically, many of these injuries could be prevented.

In Illinois: The IHIA, with a membership of approximately 400 head injured individuals, family members and professionals, recognizes the seriousness of the problem. Thousands of health care professionals across our state must deal with the results every day. Families, educators, vocational counselors, nursing homes and psychiatric facilities must struggle every day to provide for the life-long needs of those disabled by head injuries. Yet, only one in twenty of the head injury survivors receive the rehabilitation they need and deserve. The average rate of these serious injuries, that often disable our young people for life, is between 200 and 400 per 100,000. In Illinois, this means between 23,000 and 45,000 of your constituents are being seriously injured and often disabled for life each year.

Schwab Rehabilitation Center
1401 South California Boulevard
Chicago, Illinois 60608
312/522-2010

Phase Four Transitional Living Services, Inc.
7006 N. Western
Chicago, Illinois 60645
312/274-1116

Actions: When patients come to see me, I do not expect them to tell me what medication or procedure they require. They are not the experts. Similarly, as I write you, I do not presume to tell you specifically how to vote on what legislation. You are the expert. But as I do expect my patients to tell me what troubles them; what their symptoms are, I want to tell you of my concerns and I leave it in your expert hands how best to treat our nation's suffering in this "silent epidemic".

(1) Prevention: Traumatic brain injuries have existed as long as have humans and they always will. However, many today are preventable or at least could be reduced in severity. Approximately 50% of head injuries occur in motor vehicle accidents. I applaud Illinois' recent seat belt law and crackdown on drunk drivers. These laws must be enforced. I would also suggest a national mandatory motorcycle helmet law, maintenance of the 55 MPH speed limit, 21 year drinking age and air bags. While I generally dislike laws that infringe on individual's liberties, these issues do become public concerns because so many are so seriously injured that they end up on SSDI, P.A. and Medicare/Medicaid.

(2) Research/Training: While throwing money at a problem will not make it go away, a problem the scope of head injury will certainly not be touched without dollars for research and training. Currently, only approximately 112 million tax dollars are spent on all injury research with only about 4 million spend on head injury. We need more basic and applied research and more model programs. As you know, the Rehabilitation Act (HR 4021, I do not know the Senate number) is up for reapproval and the definition of "Severe Disability" (HR 4210) is being altered. We need specific recognition of the traumatically brain injured, as well as adequate funding for O.S.E.R.S., R.S.A., N.I.H.R., N.I.M.H., N.I.H., etc. I would also request that you not lose perspective with the animal protectionists. Standards for humane treatment of experimental animals is given high priority in all legitimate research and the critical need for biomedical research and knowledge must not be ignored for the sake of a few animals.

(3) Rehabilitation: Those who suffer traumatic brain injuries desperately need acute medical care, rehabilitation and extended services. We in health care are frustrated. We are trying to respond to the need for cost-efficiency, yet, when we design innovative cost-efficient treatment approaches, they are not covered in reimbursement guidelines. Medicare/Medicaid guidelines desperately need to be changed to keep pace with advances in treatment approaches. I understand your concerns about Senator Chaffee's bill (s. 873), but the principle of covering non-typical medical services is sound. Similarly, there is concern about "supported employment", but the vocational and educational needs of the head injured must be more effectively met. Private sector health insurance must also be encouraged to provide better

coverage for catastrophic events such as traumatic brain injuries. As a clinician, this is my greatest personal concern. Thousands are denied services they deserve because the services are not yet covered. Sadly, the cost of maintaining these people is greater when the services are denied than it would be if the services were provided.

(4) Life Care: Sadly, even with our best efforts, many of those with traumatic brain injuries do not recover to a level of full independence. The disabled population is growing rapidly as we are able to save more and more of our injured. As a society, however, we must begin to develop more options in living for those who are left forever changed. Currently, the choices are seriously limited. If a person can not live "independently", the only choices may be to be dependent in the family or go to a nursing home. Far too many of our head injured end up wrongly placed in nursing homes, psychiatric wards and prisons where they waste their human potential and burn-up precious public dollars. Many of these people could have supported lifestyles that would not only allow them to work around their deficits, but would let them live at their highest level of independence, find opportunities to use their remaining abilities and save a huge number of dollars in maintenance costs by returning them to productive lifestyles. This is the mission of transitional and late stage rehabilitation. We can do it, but we need support.

(5) Awareness/Advocacy: Finally Senator, I would ask you to join our effort to increase public awareness of this problem and become an advocate for those in your constituency who may not be able to speak for themselves. As I mentioned, the Illinois Head Injury Association has about 400 members and the National Head Injury Foundation has about 12,000. We are but at the tip of the iceburg of those who are touched by this tragedy. Everyone in our society is affected, at least, indirectly and NHIF has answered over 500,000 calls for help. NHIF celebrated it's sixth anniversary in Washington this week, April 16 to 19, 1986. Our conference was attended by some noteable people who spoke and received awards. Presidential Press Secretary, James Brady, was honored and did a PSA television spot for us. Senators John C. Danforth (R-Missouri) and Edward M. Kennedy (D-Massachusetts) attended, spoke and received awards, as did Representatives Steve Bartlett (R-Texas), Silvio Conte (R-Massachusetts) and Norman Dicks (D-Washington).

Later this year (November 12-14, 1986), our home state of Illinois will have the honor of hosting the sixth annual ~~NHIF Professional~~ Conference in Chicago. I will be contacting you soon to ask if you ~~might participate~~ in this conference with us. I hope you will be able to stand with us and add your strength and voice to the cry for help from the sufferers and supports. We are all touched by "The Silent Epidemic".

Thank you for your attention. If I may provide any further information or assistance, please feel free to contact me at any time.

I look forward to our next contact.

Sincerely,

Barry W. Rath, Ph.D.
Clinical Director
Schwab/Phase Four Head Trauma Program

BWR:pi

cc: Senator Alan J. Dixon
State of Illinois

Senator HARKIN. Senator Metzenbaum.

OPENING STATEMENT OF SENATOR METZENBAUM

Senator METZENBAUM. Thank you, Tom. This is an historic hearing. It is the first hearing, to my knowledge, that Congress has ever held in connection with the issue of head injury.

I think I learned more about this subject than one wants to learn when my wife had a bicycle accident and suffered a concussion, contusions, and had some seizures. It has been about 16 months.

I spoke to the head injury group last evening and said to them, "There is something different about a head injury than most other injuries. When you break an arm, you start to flex it a bit and it gets a little bit better over time. If you have a heart transplant, there is some visible way of determining the effect, how well it has been done."

Other injuries are the same. But head injuries are special and only the person who has the head injury can appreciate its impact. Suddenly, a head injury affects your eyesight—my wife still has double vision. It affects your hearing—my wife has had to get a hearing aid, never had one before.

It affects your memory, some worse than others. It affects your sense of smell, taste. It affects your memory. It affects your energy level. Sometimes you feel that you are in a time warp. And it is a different kind of injury than that which we have known about in the past.

To the credit of the people in the National Head Injury Foundation, who created this organization just eight years ago, suddenly people are coming out and indicating their concern.

More deaths occur by reason of head injuries to those under 34 than from any other reason, any other kind of accident or illness, and when you stop to think that there are a million head injuries a year and that 70,000 to 90,000 people lose their lives each year, it truly makes an impact upon you.

I do not intend to speak at length, but certainly our first witness today has experienced as much as anyone could possibly experience by the impact of a traumatic head injury, and certainly no more able spokesperson could be before us.

I just am so grateful to you, Tom, because since you have been in the Senate and I have come to know you better—I knew you in the House, but not as well—you have actually been a pillar of strength to issues of concern, to people issues in this country, and I just am grateful to the people of Iowa for having seen fit to send you here; and to your colleague on your left—maybe I had better not say that. [Laughter.]

Senator METZENBAUM [continuing]. Seated on the right from the perspective out here, he, too, has not hesitated to take the floor and to champion causes that, yes, at times were not that popular, but he thought they were right. He has been there time and time again. I am proud to be here sitting with the two of you this afternoon.

Senator HARKIN. Thank you very much, Senator Metzenbaum.

We will enter an opening statement by Senator Stafford in the record at this point.

OPENING STATEMENT OF SENATOR STAFFORD

Senator STAFFORD. Mr. Chairman, I am pleased to join with you in welcoming the witnesses today who are testifying on the very important topic of traumatic brain injury.

I also want to congratulate the National Head Injury Foundation on their long-standing efforts to provide support to the families as well as those individuals with head injuries.

Ten to fifteen years ago individuals who suffered a traumatic brain injury either died or were relegated to institutional care as services to this population were virtually nonexistent. Today the picture is brighter due to advances in medical technology as well as the availability of rehabilitation and other services within the community.

Each year over 150 Vermonters become traumatically brain injured. Unfortunately, we have only 20 beds available for long-term medical rehabilitation each year. This means that the majority of these individuals must go away from their homes for the necessary intensive rehabilitation services which will enable them to become independent, productive citizens once again.

I am very encouraged when I hear about projects such as the one in Vermont which provides extended rehabilitation and independent living services for persons with head injuries within a community living environment. This project was started just last Fall and great strides have been made with individuals who previously were in a nursing home who are learning how to care for themselves more independently. The goal for these people is to provide them with the services and assistance necessary so that they are able to move into an apartment on their own. More projects such as this are greatly needed throughout not only Vermont but the rest of this Nation.

I am sure that our witnesses today will provide the Senator with a greater insight into the problems associated with traumatic brain injuries.

Senator HARKIN. Senator Weicker.

OPENING STATEMENT OF SENATOR WEICKER

Senator WEICKER. Thank you very much, Mr. Chairman. Thank you for your gracious remarks and yours also, Senator Metzenbaum.

Let me say I never doubted when the chairmanship of the Subcommittee on the Handicapped went into the hands of Senator Harkin, that those who need special care in this Nation, regardless of for what reason, would have a fighter in their corner. This is a man of compassion, but it is also a man of extraordinary ability who can translate that compassion into reality.

I ask unanimous consent that the full text of my remarks be included in the record.

But I want to also pay a special tribute to three other persons: to Jim and Sarah Brady for all that you do. Sometimes really a formal position makes us secure and ineffective in our efforts, whereas, an informal effort is done with effectiveness and a passion that surpasses that which comes from the institutional bodies or representatives of those institutional bodies.

I have never seen two people who are so activist as the both of you, and I will mention one other person, my old friend, Jack Javits, who when he left this body, was even more effective than he was in the United States Senate.

For anybody who thinks that one person cannot do anything, all they have to do is to look at the Bradys and the Javitses of this world. Believe me, you do an awful lot.

Also, I would like to welcome especially Cindy Mulvey from East Haven, who is the survivor of a severe head injury and she has made an extraordinary recovery. She is going to be testifying here before us this afternoon.

I know that she has had a very difficult and a lonely experience, she and her family. It is great to have her here to give a message that obviously comes from the experience as it comes from the heart.

[The full text of Senator Weicker's statement follows:]

OPENING STATEMENT OF SENATOR LOWELL P. WEICKER, JR.

HANDICAPPED SUBCOMMITTEE HEARING ON

EDUCATION AND REHABILITATION OF TRAUMATIC BRAIN INJURED PERSONS

APRIL 13, 1988

WE ARE HERE TODAY TO HEAR TESTIMONY ON A TRAGIC AND GROWING PROBLEM, WHICH IS SOMETIMES REFERRED TO AS "THE SILENT EPIDEMIC"--THAT OF TRAUMATIC BRAIN INJURIES. IT WASN'T SO LONG AGO THAT MOST VICTIMS OF SERIOUS HEAD INJURIES DIED. TODAY HOWEVER, THERE ARE AN INCREASING NUMBER OF INDIVIDUALS WHO, THANKS TO RECENT ADVANCES IN MEDICAL KNOWLEDGE AND TECHNOLOGY, SURVIVE THESE INJURIES. HOWEVER, THEY OFTEN SUFFER LONG-TERM DISABILITIES.

IT IS TRUE THAT WE HAVE COME A LONG WAY OVER THE LAST FEW DECADES IN IMPROVING THE QUALITY OF LIFE FOR INDIVIDUALS WITH DISABILITIES. YET FOR THE SEGMENT OF OUR POPULATION WHICH HAS SUFFERED SEVERE HEAD INJURIES, SADLY, THIS IS NOT THE CASE. AS WE WILL HEAR TODAY, THESE INDIVIDUALS OFTEN FACE A LIFELONG STRUGGLE TO REGAIN PHYSICAL, INTELLECTUAL, AND EMOTIONAL INDEPENDENCE FOLLOWING THEIR ACCIDENTS.

THE NEEDS OF THE TRAUMATICALLY BRAIN-INJURED ARE CONSIDERABLE AND COMPLEX, BECAUSE OF THE EXISTENCE OF IMPAIRMENTS IN INTELLECTUAL AND COMMUNICATIVE ABILITIES, AS WELL AS UNIQUE SOCIAL AND BEHAVIORAL CHARACTERISTICS. BUT, OUR REHABILITATION SYSTEM IS NOT GEARED TO MEET THESE DIVERSE PROBLEMS--IN FACT, COMPREHENSIVE REHABILITATION SYSTEMS FOR THE TRAUMATICALLY BRAIN INJURED ARE

NONEXISTENT IN SOME STATES AND INADEQUATE OR FRAGMENTED IN MANY OTHERS. AS A RESULT, IT IS OFTEN ONLY THOSE FAMILIES WHO DETERMINEDLY LEARN HOW TO "WORK THE SYSTEM" THAT FIND APPROPRIATE CARE.

WE HAVE AN OBLIGATION TO PROVIDE A COMPREHENSIVE AND COORDINATED SYSTEM OF CARE TO THESE INDIVIDUALS. THAT SYSTEM MUST PROVIDE A CONTINUUM OF CARE FROM EMERGENCY MEDICAL CARE TO REHABILITATION AND EDUCATION, INCLUDING ASSISTANCE WITH INDEPENDENT LIVING AND JOB TRAINING. IT MUST ALSO INCLUDE INJURY PREVENTION PROGRAMS AND TRAINING FOR OUR PHYSICIANS AND ALLIED HEALTH PROFESSIONALS. FINALLY, WE MUST SUPPORT THE ESTABLISHMENT AND MAINTENANCE OF THESE PROGRAMS AND ENSURE THAT A FAMILY'S LACK OF FINANCIAL RESOURCES WILL NOT BE A BARRIER TO QUALITY CARE AND SERVICES.

THE NATIONAL HEAD INJURY FOUNDATION HAS DONE AN OUTSTANDING JOB OF EDUCATING HEALTH CARE PROFESSIONALS, STATE AND FEDERAL GOVERNMENTS, AND THE GENERAL PUBLIC ABOUT THIS TRAGIC EPIDEMIC. THE EFFORTS OF THE FOUNDATION, ALONG WITH THOSE OF JIM AND SARAH BRADY, AND THE OTHER WITNESSES HERE TODAY HAVE RESULTED IN THE EXPANSION OF SERVICES FOR VICTIMS OF HEAD INJURY AND THEIR FAMILIES ACROSS THE COUNTRY. I COMMEND YOU FOR YOUR EXTRAORDINARY WORK AND SUCCESS THUS FAR, BUT THERE ARE TREMENDOUS CHALLENGES REMAINING. I LOOK FORWARD TO HEARING FROM ALL OF YOU TODAY, AND TO WORKING WITH YOU TO IMPROVE THE QUALITY OF LIFE FOR ALL THOSE WHOSE LIVES HAVE BEEN TOUCHED BY TRAUMATIC BRAIN INJURY.

FINALLY, I WOULD PARTICULARLY LIKE TO EXTEND A WARM WELCOME TO CINDY MULVEY FROM EAST HAVEN, CONNECTICUT. CINDY, I UNDERSTAND YOU ARE THE SURVIVOR OF A SEVERE HEAD INJURY, AND HAVE MADE AN EXTRAORDINARY RECOVERY. YET I ALSO KNOW THAT THE EXPERIENCE WAS A VERY DIFFICULT AND LONELY ONE FOR YOU AND YOUR FAMILY, AND I AM PLEASED THAT YOU ARE ABLE TO BE HERE TODAY TO SHARE YOUR THOUGHTS ON HOW WE MIGHT HELP PEOPLE LIKE YOURSELF IN THE FUTURE.

Senator HARKIN. Thank you very much, Senator Weicker. I would also ask unanimous consent that the remainder of my statement be made a part of the record. I also have a statement from Senator Simon for the record.

I also want to recognize one other individual who is with us here in the audience today, who has been a real champion, who has pushed this issue, who opened my eyes to this issue sometime ago and who still maintains a great leadership role. That is Marilyn Price Spivack, president and cofounder of the National Head Injury Foundation.

I would like now to introduce our first panelists, Jim and Sarah Brady. All of us remember that terrible day when Jim Brady was shot, only months after he had reached the pinnacle of his career as the Press Secretary to the President of the United States.

We all pulled for his swift recovery, because he was and is a competent, compassionate, and just a plain likable individual. His tenacity, his courage, his perseverance, as well as the courage and personal commitment of Sarah Brady, have inspired us all.

The Bradys have set an example for the Nation, not just in their private struggles, but in their public statements, they have been a voice of reason and moral conscience. For these reasons, I am sure their testimony will carry a great deal of weight with this subcommittee.

It is my honor, it is a privilege for this subcommittee to have the Presidential Press Secretary and his spouse, Sarah Brady, here with us today.

Welcome and the floor is yours; you may please proceed in any manner you so desire.

STATEMENTS OF JAMES BRADY, PRESS SECRETARY, PRESIDENT REAGAN, HONORARY NATIONAL HEAD INJURY FOUNDATION CHAIRPERSON, AND SARAH BRADY, HONORARY NATIONAL HEAD INJURY FOUNDATION CHAIRPERSON

Mr. BRADY. My name is Jim Brady. I am a seven-year survivor of a traumatic brain injury.

First, I want to thank you, Mr. Chairman, and members of this subcommittee for holding these important hearings and for asking my wife and me to testify. I know only too well the tragedy surrounding the head injury, and as spokesman for the National Head Injury Foundation, I have traveled around the country and met thousands of others head injured, who daily face the myriad of difficulties I myself do.

I am pleased that you are taking a keen look at our problems and feel that together we can work to seek a common good sense solution to many of them.

I want to thank you for your sincere interest in the head injured of this country.

Senator HARKIN. Thank you very much.

Mrs. BRADY. Mr. Chairman and members, you can see my husband, as a seven-year survivor, has done beautifully. I am very proud of him.

I want you to know what an honor it is for me to be affiliated with the National Head Injury Foundation, and to have this oppor-

tunity to address this committee, and I thank you very much for the opportunity.

I am sure you are all well aware of the circumstances surrounding Jim's injury. Speaking as a family member, I can tell you that going through that initial trauma is very difficult, but somehow you get through it.

Mr. BRADY. It was difficult for me, too.

[Applause.]

Mrs. BRADY. That is a hard one. [Laughter.]

Whether it be God's will or your body clocks, somehow you get your strength, and in Jim's case, the perseverance itself, brought us through it, and he was my guiding light. I watched him get better, and it made everything so much easier for me.

We certainly, beginning that day, that morning, never believed that Jim later on in the day would become a statistic in the major cause of death and disability of all people under age 35. Trauma.

In our case, we were so fortunate to have everything going for us that had been possible. There was an ambulance right there ready to take Jim to the hospital, and within 10 minutes, he was under a neurosurgeon's care.

He went to one of the finest shock trauma units in the country, he had the finest surgeon and the best, the very best of nursing care, and certainly without this, Jim would never have survived another five minutes.

From the moment each of us entered George Washington University Hospital, we entered a cocoon that we would not leave for nine months. There, we had the best of everything—medical care, the love and support of family and friends, the President and Mrs. Reagan, and people from virtually all over the world.

Jim's room was like a museum, filled with over 300 teddy bears and gifts. Things arrived that were beyond your wildest imagination. The door to his room was guarded 24 hours a day by Secret Service, and Jim was afforded every comfort imaginable.

Mr. BRADY. That was so I couldn't sneak out. [Laughter.]

Mrs. BRADY. And believe you me, toward the end he was trying.

We had a very wonderful, fortunate experience during those nine months in receiving the very best, and it was a place I felt sheltered and secure and only toward the very end, when Jim was ready to break out, and there was a petition to Free the Bear, did he feel like leaving this wonderful, secure area.

But in retrospect now, I know what I missed out on in those nine months was having a support system which, today, people under the same circumstances would be fortunate enough to have with the National Head Injury Foundation.

Nothing, or no one, prepared us for what was going to happen when we left that hospital, leaving the security and love and care of a medical community. For me, and I think for Jim, also, although coming home was the day we had looked forward to with excitement and felt our future was set, there was no way that we would ever know how difficult coming home was going to be, and for me, I had to face taking care of a head-injured person by myself—as Jim said, a large bear—by myself.

And it is a very intensely difficult thing to go through. Not knowing what course to take, I think is always the most difficult.

Certainly in the beginning, not knowing whether Jim was going to live or die was the difficult situation. Then, not knowing what lay ahead, he seemed to have so many pitfalls along the way, three or four operations, and seizures, that head-injured so often have.

And then I had to know, am I planning the right course for his recuperation? Is it better to go home and just do outpatient therapy, would it be better to go to a large rehab center somewhere? But at that time, there was no information for the head-injured at all. Head-injured were treated very much the same as someone who had had a back injury, a spinal cord injury and who was paralyzed.

I had no one to talk to, no one to ask other than our own neurosurgeon on whom I depended completely.

Jim has over the last seven years received all the therapies that he needed. We were lucky enough because we were here in Washington with the finest available, we were lucky enough to receive that, and he continues to receive all he needs.

But as we travel across the country, we meet and hear from survivors and their families that services and programs are not available to them because of eligibility, funding, geographic location of programs, lack of trained professionals, community-based programs, residential options, educational and vocational opportunities.

Families and survivors express the frustration of not having the desperately needed support and counseling programs for themselves and their families. There are lifelong issues that affect parents, spouses, children, and siblings. Keeping one's stability and security are often at risk.

Life is so very disrupted by a traumatic brain injury and it affects so many people. The general public and community at large still have no concept or understanding of the struggle survivors must face as they try to pick up their lives with dignity and purpose. And believe you me, I have watched it daily, the frustration and the pain, and I have watched Jim go through it, and he has been able to do it, I think, with a sense of humor, but that does not take away the very fact that for him it has been a painful struggle.

Mr. BRADY. She is a hell of a good watcher. It doesn't bother her, she can sit there and watch it and just watch it and watch it and watch it and watch it.

Mrs. BRADY. Now, now, we do not have to have Jackie Gleason's Honeymooners right here at the hallowed halls of Congress.

If there is anything I have learned over the past five years, it has been the importance of having a support system, and Marilyn and the National Head Injury Foundation have provided that for us.

We also want to clearly emphasize that the incidence of traumatic head injury can be greatly reduced by public attention to prevention, both by vehicular and other forms, such as gun control, which is an area that I have dedicated myself to. I know you are all familiar with that stand, that I won't go into it, but I feel that the greatest gift we can give our children and the future is a future where public safety is put tantamount and the world will be safer, both for people in cars and certainly in our city streets.

So many people are killed or permanently disabled, and yet we do not take the steps that we should to reduce injury in America.

We appreciate this committee's attention and interest on the issue presented by the National Head Injury Foundation, and we implore you to help us seek solutions in resolving the reduction of TBI, thereby reducing the tragic loss of our children, youths, and adults, and reducing a major cost to society.

Thank you again for the opportunity for letting us be here today.

[The prepared statement of James and Sarah Brady follows:]

National Head Injury Foundation, Inc.

Gerald W. Bush, Ph.D., *Chairman of the Board*
Marilyn Price Spivack, *Founder, President*
Pamela Burns, *Vice President, State Association Affairs*
James Mikula, Ph.D., *Vice President, Professional Council*
Dale Ezzell, *Vice President, Provider Council*
Charles Haynes, *Secretary*
Charles L. McLafferty, *Treasurer*
Martin L. Spivack, M.D., *Past President, Co-founder*
James and Sarah Brady, *National Honorary Chairpersons*

TESTIMONY OF

THE NATIONAL HEAD INJURY FOUNDATION

TO THE SENATE SUBCOMMITTEE ON THE HANDICAPPED HEARING

RELATIVE TO TRAUMATIC HEAD INJURY

SUBMITTED BY

JAMES AND SARAH BRADY

ORAL TESTIMONY

APRIL 12, 1988

333 Turnpike Road • Southborough, MA 01772 • (617) 485-9950

Mr. Chairman and Members,

I want you to know what an honor it is for us to be affiliated with the National Head Injury Foundation organization, and to have the opportunity to address this committee.

I'm sure you are all well aware of the circumstances surrounding Jim's injury. Speaking as a family member, I can tell you that going through that initial trauma is surely difficult, but somehow you do. Whether it be God's will or our fine body clocks, we somehow get a certain strength for that initial trauma. We never expected that Jim would become a statistic in the major cause of death and disability of all people under age 35. TRAUMA!

In our case, I felt we were so fortunate to have had everything going for us that was possible---an ambulance immediately available, two minutes to one of the finest shock trauma units, the finest in surgeons, and the best in nursing care. Without this, Jim would never have lived.

From the moment each of us entered George Washington University Hospital, however, we entered a cocoon that we would not leave for nine months. We had the best of everything---medical care, the love and support of family and friends like the President and Mrs. Reagan, and people from virtually all over the world. Jim's room looked like a museum, filled with over 300 teddy bears and gifts beyond your wildest imagination. The door to Jim's room was guarded 24 hours a day by the Secret Service, and Jim was afforded every comfort imaginable, down to his meals being served on a silver tray. I cannot tell you how fortunate we felt. It was like being in the womb; I felt sheltered and safe.

In retrospect, however, I know I missed the opportunity support systems of the NHIF and a structured system of extended head injury rehabilitation programs. Nothing, or no one, prepared us for the frustrations and problems that were ahead. Coming home from the hospital was the difficult moment of all for me. Coming home and facing it alone for the first time was hard.

Not knowing is always difficult: In the beginning, not knowing if Jim would live or die, then not knowing what lay ahead, and most frustrating of all, not knowing if the course I had helped to set for Jim's recuperation was the best. The doubts: The nagging feeling that maybe I wasn't doing all I could. Should he go to Chicago Rehab? Should he stay home with the family and our friends? Surely there must be an expert in this field who could answer these questions for me.

Jim has received all the therapies he needed, and continues to receive all he needs. But as we travel across the country, we meet and hear from survivors and their families that services and programs are not available to them because of eligibility, funding, geographic location of programs, lack of trained professionals, community based programs, residential options, educational and vocational opportunities. Families and survivors express the frustration of not having the desperately needed support and counseling programs for themselves and their families. There are lifelong issues that affect parents, spouses, children, and siblings. Keeping one's stability and security are often at risk.

Life is so disrupted after TBI, and it effects so many people. The general public and community at large still have no concept or understanding of the struggle survivors must face as they try to pick up their lives with dignity and purpose.

If there is anything I have learned over the past five years, it has been the importance of having a support system.

We also want to clearly emphasize that the incidence of traumatic head injury can be greatly reduced by public attention to prevention. Over 50% of injuries are caused by vehicular accidents. We need to pay heed to all prevention methodology. You are all familiar with our stand on gun control. So many people are killed, or permanently disabled, and yet we do not take the steps we should to reduce injury in America.

We appreciate this committee's attention and interest on the issue presented by the National Head Injury Foundation. We implore you to help us seek solutions in resolving the reduction of TBI, thereby reducing the tragic loss of our children, youths, and adults, and reducing a major cost to society.

Senator HARKIN. Well, thank you both for being here today and thank you for sharing with us your experiences of what you had to go through. It is very touching.

I think we can all see now why Press Secretary Brady and Sarah Brady are both tremendous examples for all of us in our society.

I understand you have to be in Baltimore at 3:30.

Mrs. BRADY. Shortly after.

Senator HARKIN. I am sorry we started a little bit late. I only have one question that I would like to address to you: it has to do with long-term care.

There are a lot of different things that have to be done in terms of support mechanisms for long-term care. Could you just tell me what you might consider to be the priorities? What do you see as the important long-term care needs of head injury survivors? What are the important parts of long-term care?

Mrs. BRADY. I certainly think, and I can speak only for our family, because certainly every head injury patient, although we share many things in common, there are levels of how deeply injured the person is.

In our case, home health care probably ranks the number one need. Jim, for instance, is unable to get out of a chair by himself, or would not be able to leave our home if there was a fire, for instance, unless someone were there to aid.

He has had seizures, as many head-injured people have, and I feel very strongly that we need to look at the problem of home health care very seriously. For us, that is our number one priority.

When Jim was hurt, and I think any other person who undergoes this situation, first of all, you have the trauma and then you start looking at what has happened to the person. It is a terrible tragedy to your life. Your life has changed dramatically by this, and your family's lives and your children's lives and your parents' lives. I can't tell you how many.

Jim has a mother who is now 84. It has destroyed her. We have two children, one of which is only nine years old, and it has been terribly devastating on a nine-year-old son.

For Jim, it has been frustrating. I know that he laughs and keeps a sense of humor up, but I know that he thinks daily what he could have been doing.

So you have that part of it. And then comes in all the physical hassles day to day. Whenever we go anywhere, we have to plan. I have to call and find out which door we can go in. I have to plan is there a way to get in there, how much help am I going to need to get Jim up and down stairs.

Traveling is difficult. I have to have someone in the house. If I leave, I am afraid of a fire or something in the house. I would be very negligent to leave Jim in the home alone. But I can't stay with him every moment. I have a nine-year-old son and grocery shopping and everything any other housewife has.

Then, you have financial difficulties that come in, and although we have not been faced—and I am thankful for that—as of yet to any great extent. We have to some extent. For example, when Gramm-Rudman went in, we certainly saw the brunt of that just for a very short time, and it really—I almost got angry about that.

I thought here we are, kind of down and out, and then we get another little something pushed at us.

It is very frustrating to see that home health care is not always covered. It makes it, for so many people, an only option is institutionalizing someone, and the thought of ever having to institutionalize someone as vibrant and wonderful as Jim Brady, but I think ahead to when I am 80 years old and I am not able to lift and carry, Jim would go over the wall.

Maybe there won't always be someone there to help. That worries me. Our future worries me tremendously, because I don't know that I will always be as strong and able as I am now.

Senator HARKIN. One of the reasons I asked that question was because earlier this year, under the auspices of the Villers Foundation—because of the Iowa caucuses, you will appreciate this, Jim—I got to ask each of the Democratic candidates for President, and my colleague, Senator Grassley, asked all the Republican candidates, their stand on long-term health care.

The Villers Foundation has been supporting this. When we asked the candidates about long-term care, I was amazed that every one, both sides, looked upon long-term health care only as an elderly issue.

It is not just an elderly issue. It deals with the disabled also. And this is a case in point. That is why I asked you that question; because this issue has to be highlighted.

Mrs. BRADY. And so many. As we travel and meet most of the family members here, a majority of the people who are head injured are young people between 18 and 25. And you know how, as parents, our most dreaded thing in life is that phone call in the middle of the night. There are many folks out there who have had that dreaded phone call.

And those children they worked so hard to raise are now back under their care again, at a time in life when it is more difficult for them to physically take care of them. That is something we need to look at, independent living centers, group living, I think. There must be wonderful alternative ways.

Jim and I have been to some good independent living centers. I think that is a way of the future.

Mr. BRADY. One of them had a sign on the wall that said, "Conserve water. Shower with a friend." [Laughter.]

Mrs. BRADY. I don't recall that, but——

[Laughter.]

Mr. BRADY. Maybe because you weren't looking for it.

Mrs. BRADY. I think all of us in the Head Injury Foundation learn to have a good sense of humor.

Senator HARKIN. Senator Weicker.

Senator WEICKER. I have no questions. I think the testimony is eloquent. I think it is on point. I know last year—and the point you made was right on target relative to young people—last year when we had the Catastrophic Health Insurance bill before the Senate, and I am all for catastrophic health insurance, I am all for catastrophic health insurance for the elderly of this Nation, but I raised the point, how about catastrophic health insurance for the young and disabled of this Nation where the costs are even greater.

Mrs. BRADY. Very needed.

Senator WEICKER. I was assured that this would come to a vote this year, in 1988, and the good news is that the Institute of Medicine has agreed, with a Carnegie Foundation grant, to take on the study to give the costs to the Senate of what that would entail.

But when that vote comes, here will be the mark as to whether we are a great civilization or not, because the catastrophic health insurance for the elderly, believe me, is moved by the votes. This one, when it comes up, these young people, most of them do not vote. They do not have any political clout.

So whether we want to take upon us the responsibility for our neighbor without any gain to accrue to any one of the 100 on the Senate floor.

So I am delighted that, number one, you are articulating all of this. I am delighted that especially you have put a focus on an area, the young of this Nation.

I will tell you, I suspect that something, because of your effort, Jim, because of your effort, Sarah, something is going to happen, and that is what these hearings are supposed to be about.

Mrs. BRADY. We thank you.

Mr. BRADY. Thank you, Senator.

Senator HARKIN. Senator Metzenbaum.

Senator METZENBAUM. Sarah, you mentioned that at the present time, you meet the financial obligations, and as I was sitting here, I was wondering what provision is made when the President leaves office. Has there been any? Were you alluding to something without spelling it out?

Mrs. BRADY. Well, no, not particularly. We will face next year the very same options as anybody else who had been injured in the line of duty, working for the Federal Government. Jim faces the option of retiring on disability, which would be two-thirds of his salary—it would not be two-thirds of Jim's salary—it is two-thirds of a Grade 15, which penalizes Jim, I feel, because his salary is more than that. So he would retire at less than half of his salary.

But the thing that is most bothersome to me about that, and I don't think this is an option for us—is because it precludes you earning any extra money. Jim would like to work, and I think Jim has a lot—I know Jim has a lot to contribute, and he is not ready to settle down in his bear chair 24 hours a day and watch television and become a couch potato. He wants to work.

So that retiring under disability does not seem like a viable solution for us. However, we don't know what—as Jim said, he was looking for a job when he became press secretary, and we will hit another campaign and he will look for another job.

The one difficulty I find more than anything else is with Jim being head injured, it has been very difficult for me to go out and work full time. I have not had to do it during these seven years, but I probably will in the future to help us meet our financial needs.

But to do so, I have to have someone there with Jim, and I know that this is probably something that everybody is in a Catch-22 situation. You can't earn money because you need to be at home, but yet, if you are not out working, you can't earn the money to help, and it is a very difficult situation.

Again, it is not going to be as difficult for us as it is for many of the younger people, but it is something to be addressed. I think with disability, most head-injured people want to do something productive. It may not be what they could do before, but they want to work, and to give them a cap on what they can earn outside of their disability, I think may be a little incorrect. It is not fostering the idea that people want to work, and would like to.

Senator METZENBAUM. You have been a model for the Nation and we are grateful to you both.

Mr. BRADY. Thank you, Senator.

Mrs. BRADY. It has been an honor to be here.

Senator HARKIN. We welcome Senator Stafford again who has been a stalwart champion of individuals with disabilities, who, as I said before, sadly is leaving us this year. We are going to miss him greatly.

Senator STAFFORD. Thank you very much, Mr. Chairman, for the kind words. I would like to associate myself with what Senator Weicker has just said about catastrophic health care.

I apologize to the Bradys that I was kept elsewhere until part of your statement was over, but I did get here to hear quite a little of it.

Finally, Mr. Chairman, I have an opening statement that I would ask unanimous consent might appear in the record at an appropriate place.

Senator HARKIN. Without objection it will be included.

Senator STAFFORD. I have no questions.

Senator HARKIN. Thank you. Again, you are both wonderful—what can I say—you are just both wonderful.

Mr. BRADY. Thank you, Senator.

Mrs. BRADY. Thank you.

Senator HARKIN. Why don't we all show our appreciation.

[Applause.]

Senator HARKIN. We would next like to call on our panel Dr. Larry Marshall, a neurosurgeon with the University of California at San Diego.

Dr. Marshall will present testimony on the general nature of the psychological, social, and medical problems that head injury survivors face.

Dr. Marshall, welcome to the subcommittee.

Without objection, your statement will be made a part of the record in its entirety. If you could summarize it for us, we would be most appreciative.

STATEMENT OF LARRY MARSHALL, M.D., DIVISION OF NEUROSURGERY, UNIVERSITY OF CALIFORNIA, SAN DIEGO, CA

Dr. MARSHALL. Thank you.

Senator Harkin, distinguished members of the Subcommittee on the Handicapped: I am a neurosurgeon. I take care of those who are acutely ill.

Because of legislation enacted by the Congress in the 1970's, the Emergency Medical Services Act, the number of people who die from head injury in this country has fallen dramatically, but in

many ways we have increased the agony for those who survive and for the families around them.

We have a system of health care that is front-loaded. It has paramedics, trauma surgeons, neurosurgeons. And yet we have a great chasm in health care, because following the acute hospital experience, most people fall into an abyss from which very few emerge.

Let me illustrate my point by giving you a brief case history of a young man who wanted to be a physician, a university student who when riding his bicycle home from his classes was struck by a car. He was brought to the University of California Medical Center with a severe head injury, an intracranial hemorrhage, and was operated on for his hemorrhage.

He was placed in a medical coma, a technique developed with support from the National Institutes of Health. Following a hospitalization of four months and an expenditure of in excess of $250,000, he went to an acute rehabilitation hospital for two months of rehabilitation.

What then befell this young man? He fell into the abyss that I described. At the age of 21, he lost his health care coverage because he was no longer covered by his parents. He was ineligible for vocational rehabilitation. He could not qualify for residential treatment facilities.

He could not qualify for transitional living because his mother made about $700 more than the maximum permitted by law.

What has happened to this young man? From our perspective, superficially, as a neurosurgeon, he has made a moderately good recovery. In his terms, what has happened? In December of 1987, he tried to kill himself.

Why does that happen? It happens because the physical disability that characterizes the events that Senator Metzenbaum described, the cast on the limb makes it obvious to those who see the wounded, that they are injured.

But what happens to the head injured? What happens to the head injured is that most of the physical wounds heal, they disappear. Most patients with head injury are not physically disabled to a great extent, but they are left with profound intellectual and mental disability.

As Senator Weicker so eloquently said, a civilized society is judged by how it treats its less fortunate and those who are incapable of being their own advocates.

The present health care system copes quite well with acute disability, and as emergency medical services system proliferate, the number of head-injured survivors will continue to increase.

But ironically, we have a system that produces increasing heartbreak. We have no comprehensive mechanism to deal with the intellectual and mental or behavioral disturbances of head injury which would be amenable to rehabilitation.

We have no mechanism to deal with returning these people to a productive role in our society. We are warehousing people in the United States who could be productive members of their family and productive taxpayers.

This is not necessary. It is extremely expensive in the long term and yields a byproduct which we all view as unfavorable.

Many societies, allies of ours in all kinds of endeavors have developed a more logical and reasonable approach to the care of patients with intellectual and behavioral disturbances, and have made remarkable strides in rehabilitating them.

This society, the leader in the development of acute care in the world, has done an extremely poor job in providing rehabilitative and transitional living facilities for the head injured.

I urge your consideration of several of the bills that are pending before this Congress.

Thank you, Senator.

[The prepared statement of Dr. Marshall follows:]

86-558 0 - 88 - 2

Senate Subcommittee on the Handicapped - Senator Harkin, Senator Weicker

Testimony of Lawrence F. Marshall, M.D., April 12, 1988

As a neurosurgeon who has spent much of his career attempting to improve the outcome of head injury, I am grateful to have this opportunity to share with you my thoughts on these truly neglected victims of an American epidemic and to answer any questions that you might have. In the early 1970s the Congress of the United States, concerned about the toll of traumatic injury and other medical catastrophes, enacted legislation which brought about literally a revolution in prehospital care. This effort, which resulted in the development of regional plans for emergency medical services, has led to the development of systems of care for trauma victims. In some regions of the United States these systems are the best in the world, and improvements in other geographic areas are coming rapidly.

Coincident with changes in prehospital care, the National Institutes of Health, through funding authorized by the Congress and signed by the President, targeted a reduction in the mortality from Central Nervous System injury as one of its priorities. Demonstration projects conclusively showed that the mortality from severe head injury could be substantially reduced by coordinated effort in both the prehospital and intensive care unit phases of the patients' care.

Head injury, like another epidemic which is striking fear into the hearts of many Americans, robs the nation of its youth. Head injury is a disease of the young, with the majority of patients suffering such injuries between the ages of 15 and 30, but one that strikes at all ages and at all levels of

society. Each year approximately 110,000 Americans die of head injury. It is the leading cause of death from trauma and, taken on its own, would represent the fourth leading cause of death in the United States. Perhaps even more than the tragedy of young lives being snuffed out before their prime, are the morbid consequences of head injury which affect even greater numbers. A minimum of 75,000 Americans of all races, creeds, and political affiliation are left with serious and life long consequences of such injuries. For a few, when unique family and social resources exist, the struggle to regain one's identity and at least a portion of one's former intellectual capacity is made possible. For the great majority, the work is left undone. It is as if God had created Man and Woman with only three limbs. The work is not only undone, the lack of social and behavioral services for these victims has, in many instances, created a chasm of despair which leads to a many-fold increase in divorce, suicide, family violence, and other symptoms of social disintegration.

One might ask if these sequelae are the inevitable product of head injury. The answer is a resounding, "no." Some initiatives, in part sponsored through the efforts of the Federal government, and some in the spirit of the President's call for increasing activity in the private sector, have demonstrated that much can be done to build a bridge across the chasm which the long term rehabilitation and care of such patients requires. The costs of doing nothing are clearly enormous. In 1984, the Australian insurance industry completed a study which indicated that, for patients who are unable to care for themselves, each patient over his life span would cost society, or the insurance industry, in excess of 1.2 million Australian dollars. A recent report from the United States paints an even grimmer picture of the financial consequences of our lack of rehabilitation and residential programs. In most

instances, this is a needless expenditure because with a much smaller investment in rehabilitation, temporary residential treatment and transitional living, as well as social services, the great majority of such patients can be made to function independently.

Given the present fragmented and incomplete system of care, we as a society are spending enormous numbers of dollars in order to either warehouse these people or try to repair the social damage that results from our lack of services. It is, perhaps, ironic that a neurosurgeon whose focus is of necessity primarily in critical care and acute care of the sick and injured, comes to speak with you today. It is evidence of the depth and the breadth of the problem for those of us who in some small way have been responsible for the increased salvage of these patients. When parents say after many months, regarding a patient whom we believe a decent recovery has been made, that they wish that their child had not survived because of the social and societal hurdles which are in the way of getting those services which will make these people whole again, it is heartbreaking. Heartbreaking not only for the parents and, perhaps, most importantly for the patient, but also for those who work in the hospital, the nurses as well as the physicians, because so much effort, both in terms of time, resources, energy, and commitment seems to flow down a drain that county and state programs seem not to have been able to close.

To put into place in many regions of the United States the technology and the resources to deliver the highest level of care currently possible for the badly traumatized head injured and multiple trauma patient, and then to do almost nothing once these patients leave the hospital is unacceptable. We have a depressing record in rehabilitation, transitional living, and other related social services. This inequity has major and deleterious conse-

quences, not only to the individual but also for society. The consequences can be measured in terms of human suffering, and they can be measured in terms of dollars. Money spent wisely and prudently in developing comprehensive rehabilitative and social services will save countless millions of dollars, not years from now but in the months following a patient's discharge from the hospital.

Most patients have the potential to become productive tax paying members of society in a relatively short time, given initial support in the critical recovery period. Is it not wiser and more prudent to make such an investment, rather than spending much larger amounts of money later, which accomplishes much less?

I urge you to finish the work began almost two decades ago through the Emergency Medical Service Act by supporting funding for these essential programs in rehabilitation services.

Senator HARKIN. Dr. Marshall, thank you, and thank you for coming this distance to be here today and for your testimony.

You touched on something briefly. I wonder if there is any more elaboration that is needed. As you said, after a head injury, the physical wounds heal up. A lot of times you don't even know, looking at an individual that he or she has been injured.

But beyond that, as a neurosurgeon, can you tell us, what makes the rehabilitation, education, care, the long-term care of a head-injured person so complex? What is it that makes it so difficult?

Dr. MARSHALL. Well, that is a good question, Senator. I think that, one, the brain is terribly complex, as we all know. There is no other disability, perhaps with the exception of stroke which tends to strike those who are more senior in our society, that affects the physical, intellectual, and behavioral characteristics of man.

I think that we have gotten pretty good at recognizing physical disability and developing treatments for it, but for intellectual disturbances, we are in an embryonic stage, the same stage that we were in perhaps 50 years ago with anemia and leukemia, but substantial progress has been made and we are not able to translate that progress into the clinical care arena, because the resources have not been provided.

I think that is one issue. I also think that we have tended to categorize all disabilities as one great lump, and the recognition that these hearings have provided to the issue of head injury, I think will help greatly in making people aware of the fact that head injury is unique, in that it alters the individual.

Perhaps one way to describe it would be the way the head injured describe themselves, and that is, that they look all right, but they are not all right. They are different. They are different people. They emerge as someone different than the one that you knew before.

That makes the interaction with the society complicated, it makes their rehabilitation complex, and as Senator Metzenbaum has unfortunately learned, it makes the interaction of the family members totally different than it was before.

I think we are not used to dealing with changed human beings, but people who suffer severe injuries are changed human beings. They are not the same person they were before their injury.

Senator HARKIN. Thank you, Dr. Marshall.

Senator Weicker.

Senator WEICKER. Dr. Marshall, do you believe the inadequacy of services has more to do with the lack of commitment to funding of those services, or is it more a result of not knowing what types of services are needed, or a combination of the two?

Dr. MARSHALL. I would say, Senator Weicker, that it is a combination of the two. It is a tortured web for the head injured. I think that one is that they have a great deal of difficulty, both they, because of their disability, and their families in finding their way through the myriad of programs that exist.

The second is a fundamental lack of funding. For example, in California, we have a progressive cutback now in what are called the community medical services fundings available to the counties, which has had a devastating effect on any kind of long-term treatment services for these people.

It has absolutely undercut a very minimal level of support. So I would say it is both.

Senator WEICKER. Thank you very much.

Senator HARKIN. Thank you, Senator Weicker.

Senator Metzenbaum.

Senator METZENBAUM. Doctor, if I could author one piece of legislation and get it through, what would you think would be the most important thrust of that bill?

Dr. MARSHALL. Well, I think the catastrophic care bill that is pending before both parts of Congress, with not just the elderly included but because of the way that Medicare covers those who are disabled, I think the inclusion of services with that bill for the severely head injured would be the most rapid partial remedy for what confronts the families, as well as the head injured, who, as you have heard this afternoon, tend to be young and not very good advocates for themselves.

I think that would be the most effective partial fix, if you will, of the problem.

Senator METZENBAUM. When it comes to comprehending the brain, how far along are we?

Dr. MARSHALL. It depends on what you measure it against, Senator Metzenbaum. I would say that we have made tremendous progress in the last 20 years in understanding the basic phenomena of the brain and also things like learning and memory, which are critically important to the head injured.

I also think that there are some things immediately on the horizon in terms of pharmacologic therapy which might mitigate some of the acute damage of head injury in the areas of memory and thinking.

We have a long way to go. I think we have a very good Federal effort from the National Institutes of Health and the National Institutes of Mental Health in addressing some of the fundamental basic problems.

We have a lot of knowledge now. If we had a system for getting it to the victims, we could do a tremendous amount to improve the quality of their lives and the quality of their families' lives.

Senator HARKIN. Senator Stafford.

Senator STAFFORD. Thank you.

Dr. Marshall, when a person receives a critical head injury, what is the most critical time after the injury has been initially stabilized?

Dr. MARSHALL. Well, neurosurgeons have a bias towards acute care, but I think we are increasingly concerned that the first several months following the injury are critically important.

We do not understand relearning. We don't understand brain regeneration. Clearly, people are left with severe and disabling injuries who make remarkable recoveries. So, I think that while I, by the nature of my specialty and my training, have tended to focus on the first few days, I think that is too limited and we need to look at the first few months.

Senator STAFFORD. Thank you very much.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you very much, Senator Stafford.

Dr. Marshall, unless you have anything else, again, we appreciate your time, your expertise, your involvement in this, and believe me, we will be calling on you again in the future.

Dr. MARSHALL. Thank you, Senator.

Senator HARKIN. I would like to call our second panel which will address the problems encountered by head injury survivors and their families.

First, Cindy Mulvey, a young woman who herself has survived a head injury; Dr. Jerry Bush, the outgoing Chairman of the Board of the National Head Injury Foundation, and Charles Haynes, the incoming Chair.

Both Jerry and Charles are parents of survivors of head injuries and will discuss some of the problems that victims of head injuries and their families experience in getting appropriate rehabilitation services.

Again, we want to welcome you all.

I would like to ask to be included in the record at this point a statement from Senator Lloyd Bentsen on behalf of Mr. Charles Haynes, for whom he has very kind words, also he lends his support to our efforts to address this problem.

I would like to insert that in the record at this time.

[The prepared statement of Senator Bentsen follows:]

Statement by Senator Lloyd Bentsen
on behalf of Mr. Charles Haynes
incoming Chairman of the Board,
National Head Injury Foundation
before the Subcommittee on the Handicapped
April 12, 1988

Mr. Chairman, as you convene these hearings today to explore the many complex issues relating to the education and rehabilitation of persons with head injuries, I am pleased that the Subcommittee will take advantage of the expertise of a fellow Texan, Mr. Charles Haynes. As the incoming Chairman of the Board of the National Head Injury Foundation, and as one who has personal experience with the trauma and misfortune connected with serious head injuries, Mr. Haynes is well qualified to discuss the problems encountered by head injury victims and their families, and ways to remove the barriers to services that they often face.

I applaud Senator Harkin and the entire Subcommittee for holding these hearings. You are raising some important issues and I look forward to working with the members of this Subcommittee in crafting legislation that will address these issues and generate positive results and new opportunities for head injury victims and their families.

Senator HARKIN. Thank you all for coming.

I would first call on Cindy Mulvey, who is from East Haven, Connecticut.

Thank you for coming; please proceed as you so desire.

STATEMENTS OF CYNTHIA MULVEY, EAST HAVEN, CT; GERALD BUSH, PH.D., NHIF CHAIRMAN OF THE BOARD (OUTGOING), HELLER SCHOOL, BRANDEIS UNIVERSITY, WALTHAM, MA, AND CHARLES HAYNES, NHIF CHAIRMAN OF THE BOARD (INCOMING), HOUSTON, TX

Ms. MULVEY. Thank you, and thank you for your kind letter, Senator Harkin, and thank you for your kind words, Senator Weicker.

Okay. My name is Cindy Mulvey and I am from East Haven, Connecticut. I would like to share my story with you.

In 1981, I was 19 years old. I had finished a year of college and I was working, saving money to continue. On December 5th, my car hit a trailer truck that was making an illegal turn, and my life changed forever. I was traumatically brain injured.

The way I look at it now, my life began with my accident. I don't really think about the person I was before, I used to run track, and now I can't run anymore. What I think about now is that I was in a coma for six weeks and doctors were telling my mother if I was going to make it, that I would be a vegetable.

I think of how badly disabled I was then and how far I have been able to come, but it has been a double challenge for me and my family. I had to fight to get better and at the same time, fight to get the help that I needed. Some I got and some I did not.

After two months in Yale New Haven Hospital and four months at Gaylord Rehabilitation Hospital, I went home. I still couldn't walk independently or speak clearly. I couldn't make my body and my mind work together to do everyday things like write or type normally, use a can opener with ease, hold a glass of water without spilling it, and dial a phone number without forgetting what I was going to dial.

When I returned home, I went to the Easter Seal Rehabilitation Center as an outpatient. My companions there were mostly children who had disabilities since birth, or adults recovering from a stroke or various injuries.

There were programs to improve my physical, occupational therapies, but there was nothing for cognitive rehabilitation which is needed for traumatic brain injury. So my family helped me do things on my own.

I practiced handwriting, copying the words out of books, like Murphy's Law, which I could relate to at that time. I practiced the alphabet, my signature and the vocabulary words in "Reader's Digest." I got a tutor for reading and math.

But I never had the special kinds of cognitive rehabilitation. I had certain kinds of problems with sequencing and ordering facts, processing numbers. Someone suggested that I play the recorder to help my sequencing, but I learned the recorder, but my sequencing ability did not get better.

I wish instead someone would have taught me how to compensate for my inabilities in sequencing, such as in typing skills, which would have been very helpful, but there was no one to show me that.

When they discharged me from the rehab hospital, doctors told me I will always walk with a limp. I decided to keep on with my so-called physical therapy, and I started going to the "Y" and working out on Nautilus to improve my coordination. I got stronger, but my coordination did not improve.

So I kept up with the Nautilus and swimming to keep in shape.

When I recovered enough to think about my future, I went to the Department of Rehab Services. It took me nearly a year to get through all the red tape, and at the end all they did was offer me a workshop for the retarded, which wasn't for me.

One of my nurses suggested that I do volunteer work at the hospital where I was a patient. I applied for a volunteer job on the Neurosurgical ward at Yale New Haven Hospital. I have gotten awards for the work that I do there. I also have a part-time job stock clerking at a supermarket, but the hospital work is much more rewarding.

As volunteer, I can give support to the patients, but my ability there is limited because I am not licensed and do not have the schooling to back me up.

I think about the future and I have my doubts. I think about going back to school, and that doesn't look like it is there for me. I think about it has been seven years since my injury, so I should be moving on, preparing for a career and to be on my own with a good job.

I know I am going to need help. It is frustrating to know there are brain injury programs out there to help with independent living or learning problems or finding jobs, but they are too expensive and, for the most part, from out of state or out of New Haven.

I have been going to support groups for brain injury survivors and families for about six years, and if there is one thing I could say about getting through brain injury, for myself and for others, but there are not enough services to help you, you know, through your injuries, to get through life.

There was nobody to be "on my case," which would have helped me out, to tell me where to go, to help out with coordination, like going to the "Y." Working on strength, I got stronger, but it did not help my coordination. If there was someone there to direct me it would have been helpful.

Two years before my accident, my sister, Nancy, was also brain injured in an accident. She was in a coma for three weeks. Other than physical therapy and occupational therapy, she did not receive help. She went out on her own.

I am proud to say that, I have come as far as I have on my own, but it would have been easier and who knows how much more successful with help. You lose so much with brain injury—your friends, your plans, your abilities, your personality—but one thing is you don't lose hope.

And I hope you can help me and others.

Thank you for your attention.

[The prepared statement of Ms. Mulvey follows:]

CONNECTICUT TRAUMATIC BRAIN INJURY ASSOCIATION, INCORPORATED
1800 SILAS DEANE HIGHWAY, SUITE 222
ROCKY HILL, CONNECTICUT 06067
PHONE (203) 721-8111

TESTIMONY

TO THE SENATE SUBCOMMITTEE ON THE HANDICAPPED -

HEARING RELATIVE TO TRAUMATIC BRAIN INJURY

Submitted by

Cindy Mulvey

April 12, 1988

My name is Cindy Mulvey. I'm from East Haven, Connecticut.

In 1981 I was nineteen years old. I had finished a year of college and I was working - saving money to continue. On December 5 my car hit a trailer truck that was making an illegal turn, and my life changed forever. I was traumatically brain injured.

The way I look at it now, my life began with the accident. I don't think of the person I was before - like I used to run track, and now I can't run anymore. Mostly I think of how I was in a coma for six weeks with the doctors telling my mother if I was going to make it I would be a vegetable. I think of how badly disabled I was then and how far I've been able to come - but it's been a double challenge for me and my family. I had to fight to get better and at the same time, fight to get the help I needed.

After two months in Yale New Haven Hospital and four months at Gaylord Rehabilitation Hospital, I went home. I still couldn't walk independently or speak clearly. I couldn't make my body and mind work together to do everyday things like write, type, use a can opener, hold a glass of water, look up and dial a phone number.

When I returned home I went to the Easter Seal Rehabilitation Center in New Haven as an outpatient. My companions there were mostly children who had disabilities since birth, or adults recovering from stroke or broken bones. There was no program there to combine the physical, occupational and speech therapy I got with the cognitive rehabilitation needed for traumatic brain injury. So my family helped me do some things on my own.

I practiced writing - copying words out of books - I remember Murphy's Law was one of my favorites. I practiced the alphabet and my signature. I did the vocabulary words in "Reader's Digest" - I got a tutor for reading and math. But I never had the special kinds of cognitive rehabilitation designed for traumatic brain injury. I had special problems with sequencing - ordering facts or processing numbers. Someone suggested to my mother that playing the recorder might help. I took lessons and I can now play the recorder, but my sequencing ability didn't improve. I wish instead someone would have taught me how to compensate for sequencing skills in a more practical way - like learning how to type. When they discharged me from rehab, doctors said I'd always walk with a limp. I decided to keep up with my physical therapy on my own. I started going to the "Y" and worked on Nautilus to improve my coordination. I got stronger, but my coordination didn't come along as I hoped. I still work out to keep in shape.

When I recovered enough to think about the future I went to the Department of Rehab Services. It took me nearly a year to get through the red tape there, and at the end they offered me a sheltered workshop program for the retarded.

One of my nurses had said "why not do volunteer work?" Five

years ago I applied for and got a volunteer job on the Neurosurgical unit at Yale New Haven Hospital. I've gotten awards for the work I do there. I now have a part time job stock clerking at a supermarket, but the hospital work is much more rewarding. As a volunteer I can give support to patients with brain injury, but my ability to help is limited because I am not licensed.

I think about the future and I have many doubts. I know I can't live with my mother forever. I think about going back to school, preparing for a career. It's eight years since my injury and I'm still improving, but to be on my own, with a good job, I know I'm going to need help. It's frustrating to know that there are brain injury programs out there to help with independent living or learning problems or finding jobs, but they're very expensive and most are far from New Haven or out of state.

I've been going to support groups for brain injury survivors and families for about six years. If there's one thing I could say about getting through brain injury - for myself and most of the others I've met in these groups, it's this: There aren't enough services, the ones that are there are too expensive for most of us, and most important, there's no one to "be on your case," to help you find what you need to recover. Two years before my accident my sister Nancy was also brain injured, and was in a coma for three weeks. Other than physical therapy, she didn't get any help.

I'm proud to have come as far as I have, and proud that I've done a lot of it on my own - but, it would have been easier and who knows how much more successful - with help. You lose so much with brain injury - your friends, your plans, your abilities, your personality - but you don't lose hope.

I hope you can help all of us. Thank you for your attention.

Senator HARKIN. Thank you very much.

Senator Weicker.

Senator WEICKER. Thank you very much for your statement, Cindy. Let me just be very brief and to the point. At this stage of your life, what would you like, if you had to put out on the table what it is that you would like to have available to you, what would you choose?

Ms. MULVEY. I am not really sure what I would like. I know from what I have been through, that I enjoy helping people, and through support groups, I find that is rewarding to me. I enjoy that work, but it is not a career. So I really don't know what I am actually looking for. I need on-the-job training, because schooling doesn't look good for me.

Senator WEICKER. The programs that do exist, is one of the reasons why they are not available to you, because they are too expensive, in other words, is private rehabilitation out there, but too expensive to get?

Ms. MULVEY. I haven't seen any on-the-job training, that was able to suit me. It wasn't really the money problems too much with me. I know for a lot of others, it is a severe problem, but right now, as far as right now, it is not a problem.

Senator WEICKER. Do you feel you need further schooling to go ahead and get yourself a job?

Ms. MULVEY. I would need definitely to know more, I think, schooling, if I wanted to go out in the world. I mean it is okay, what I do now as a volunteer, you know, which is, you know, doing okay, but it is not getting anywhere in life.

Senator WEICKER. Well, as I understand it from your testimony, you do volunteer work at Yale New Haven Hospital.

Ms. MULVEY. Right.

Senator WEICKER. And then you have a part-time job as a clerk in a supermarket?

Ms. MULVEY. Right.

Senator WEICKER. That, you get paid for.

Ms. MULVEY. Yes.

Senator WEICKER. Do you live at home with your family?

Ms. MULVEY. Yes, I live with my mom.

Senator WEICKER. When you say you would like to have on-the-job training, let me just take that one step further. What kind of a job?

Ms. MULVEY. I was looking into—I enjoy talking with people (counseling,) but I don't know, how far I can go with that, for a job.

Senator WEICKER. Well, I appreciate your being here and telling of your story, as indeed, I appreciate all those that have attended the hearing, and especially again to our chairman for raising an issue that has not had the spotlight turned on it.

I do not worry about what I can do in terms of assisting the chairman relative to funding and programs. It is a little bit more difficult for me being here in Washington to attend to the individual situations that occur within the State. I want you to stay in touch with my office to see if we can be of any assistance to you in what it is that you want to go ahead and achieve.

I do not know, very frankly, what is out there, but I think that—not just this particular area—but in so many other areas that have

been my life's work here in the Congress, something can be found. You let us work on the policy, right now I gather from the tone of your speech and what you are talking about, there is a frustration here that you feel that you can really do something, and you do not feel like you are really doing it all.

Ms. MULVEY. Yes, I feel I can do more, but I can't.

Senator WEICKER. Well, then let's get away from the national policy and let's just talk about Cindy Mulvey, and so, sometime in the next couple of weeks, I am going to have somebody from my office in Bridgeport get in touch with you. Okay?

Ms. MULVEY. Thank you.

Senator HARKIN. Senator Stafford.

Senator STAFFORD. Thank you, Cindy, for a very moving statement.

Ms. MULVEY. Thank you.

Senator STAFFORD. I note you must be 26 years old now from the time of your injury. Might I ask how old your mother is?

Ms. MULVEY. She is 62.

Senator STAFFORD. Is she self-supporting?

Ms. MULVEY. Yes. Well, she works. My father is deceased. He died 11 years ago. He had cancer. She is getting a pension, but she is also working, and, finding it kind of tough.

Senator STAFFORD. How about your sister, who was also injured?

Ms. MULVEY. She is not living at home. She is on her own.

Senator STAFFORD. She is self-supporting?

Ms. MULVEY. Yes.

Senator STAFFORD. Well, all I can say is, if Senator Weicker concentrates on helping you, I do not know of anybody who is more capable of doing it.

Ms. MULVEY. Thanks.

[Applause.]

Senator HARKIN. Thank you very much, Senator Stafford.

I have just one question for you, Cindy. I will hold off on my question to get to our other two panelists. I had wanted to accommodate Senator Weicker, who I know has another scheduled thing that he has to attend to, and I knew that he wanted to talk to you here.

I will now turn to Dr. Bush, who is next on our witness list. He is the outgoing chairman of the board of the National Head Injury Foundation. I understand that your son received a head injury at the age of 17 and never returned to school after that.

Dr. Bush, again, welcome. Thank you for all you have done. A copy of your statement will be made a part of the record in its entirety. Please proceed and summarize, if you will.

Dr. BUSH. My son would wish to correct you. This is Patrick, who was 18 at the time he was hurt. He was between high school and college.

Senator HARKIN. Eighteen. I never was good at math.

Dr. BUSH. The precision of that is probably more important to him than the precision of either of our ages, Senator.

Mr. Chairman, gentlemen, it is a great pleasure to be here today for this historic set of hearings, on the first day that I can refer to myself as former chairman of the board of the National Head

Injury Foundation. I am not only outgoing, I am gone for now 22 hours.

I would like to introduce formally my son Patrick. It is Patrick and Cindy, thousands of other survivors, and I might add the some 750,000 persons who are yet to be hurt in 1988 by head injury, that are the reason that we are here today.

If I may, I would like to enter a statement from Patrick in the record. Patrick prepared this statement working with his therapist for testimony last fall. However, those hearings never happened in the House because of a snowstorm.

When I talked to him 10 days ago about speaking at this occasion, he indicated that his statement said just about everything there is to be said.

Senator HARKIN. Without objection, that statement will be made a part of the record.

Dr. BUSH. He wrote at that time, and would like to have me read today, since he cannot speak:

> On July 19, 1980, I was hit in the head when a 20-pound pipe fell 50 feet from a rig in a Texas oil field. Since then, I can't walk, talk, move my right arm, see correctly, nor read and write as well as I used to.
>
> It is hard for me to go lots of places because of my wheelchair. It is also hard for people to understand me every place I go, because I can't talk.

End of his statement.

Gentlemen, I submit that those who cannot count, must count for a great deal in America, those who cannot speak have a great deal to say to all of us, and those who cannot stand, stand for a great deal.

My wife Jean and I would like to thank Marilyn and the National Head Injury Foundation for being there for us in 1980 when Patrick was hurt on his summer job between Middlesex School and Middlebury College, the latter of which, of course, he never attended.

All of us associated with head injury and the Foundation hope that we will be there for the 50- to 70,000 people who will be moderately to severely head injured this year. You have it within your power in the United States Senate to help prevent at least half of these if you convince the Administration to move on mandatory seat belt use in all American automobiles, air bags for automobile driver and front seat occupants, helmets for motorcycle riders, and joining us in our urging of helmet use for bicycle riders, a situation which Senator Metzenbaum so tragically knows.

Can you imagine in your wildest imagination the human suffering, those midnight telephone calls that all of us have received, and the money that would be saved by an adequate prevention program in the United States of America.

The question we have is why haven't we moved to live with automotive technology rather than to die and to be maimed by the thousands by that technology.

I also urge you to support in every possible way maximum community participation for the disabled. There certainly is a place for the rehabilitation facility divorced from its community roots. However, the major thrust of Congressional weight should be behind community integration, community-based programming, jobs, and

an integrated wholistic system of care from trauma scene to community reintegration.

This, of course, means to us two things: an active commitment to implementation of Section 504 of the Rehabilitation Act. The override of the veto in the Civil Rights Restoration Act was a great step, but there is much more to be done.

We also need Congressional approval of a system of care for the head injured, parallel to that provided to those who have experienced spinal cord injury. Accomplishing one without the other is only half a loaf.

If the United States Senate asks, "You only get a half a loaf, which do you prefer?" I would say give us our system of care and we will tenaciously pursue implementation of Section 504 and the civil rights of the disabled.

But Civil Rights, Section 504, must be implemented in jobs in order to help Patrick, in order to help Cindy, and the thousands of others in housing, transportation, education, and recreation.

It is time for the Senate to think seriously of affirmative action for the disabled, affirmative action in education, housing, and employment. Civil rights and a system of care are essential to the dream we speak of for our loved ones.

If I may, I would like to share with you two questions I have been asked and asked and asked as I travel around the United States for the NIHF. The first is: "Why does my son, daughter, husband, wife, or parent fall between the cracks of the service delivery and funding sources system?"

We have a terrible nonsystem of care when viewed from the consumers point of view. We have an equally traumatic nonsystem of funding when viewed from the parental point of view. The Federal treasury needs a guard, and I think we all agree with that, but that guard is adequate prevention. It is not the systematic denying of Federal benefits and providing only random services to those least able to make it for themselves without assistance, the disabled.

Progress cannot be made in regard to this question unless and until Congress mandates a model system.

The system needs a new and overall look based on the outstanding comprehensive rehabilitation system in place for other disability groups.

The second question is: "Gerry, what is going to happen when I die?" Americans are and have been and will continue to be very creative, especially when faced with tragedy. The tremendous growth of the National Head Injury Foundation under Marilyn's leadership proves this.

Thousands of us from all parts of the United States have grown together. We have bound ourselves together for self and mutual help in the absence of outside help, but we, the Jean and Gerry Bushs of America, cannot help our loved ones when we are dead.

And we parents are scared beyond your infinite capacity to comprehend about what is going to happen to Patrick, to Cindy, and the others when we are no longer here to care for them. These are citizens, and we are so afraid of the day that the fragmented nonsystem of Government intervention will put our children in mental hospitals or other kinds of huge, barbaric, isolated institutions.

Gentlemen, I have had no answers to these two questions which I am asked and asked and asked: "Why do we fall through the cracks? What happens when I die?"

I know the answer lies in civil rights for the disabled and in a total system of care. The magnitude of the national epidemic of head injury demands a comprehensive system of care, and we, in the Foundation, pledge our help and support in any way possible to help you, the Senate of the United States, achieve it.

Thank you very much.

[The prepared statement of Dr. Bush follows:]

Toward a System of Care and Civil Rights

Statement for The Record

United States Senate
Committee on Labor and Human Resources

Subcommittee on the Handicapped
Senator Tom Harkin, Chairman

by
Gerald W. Bush, Ph.D.
Chairman of the Board, National Head Injury Foundation
Director, Employee Benefits Program
The Heller School
Brandeis University
Waltham, MA 02254
(617) 736-3790

April 12, 1988

INTRODUCTION

The mission of the National Head Injury Foundation is:

> to improve the quality of life for persons with head injury and their families, and to develop and support programs to prevent head injury.

In pursuit of this mission the Foundation has structured itself into a survivor's council, a professional's council, a provider's council and a state association's council. Each of these four constituent parts of the whole have representation on the Board and the Executive Committee of the Foundation. Thus the Foundation represents all direct head injury interests.

In pursuit of its mission there are three major areas in need of Congressional consideration:

1) a coherent, adequately funded "system of care" for those who have experienced head injury and their families.

2) an ideology to guide Congressional actions; and,

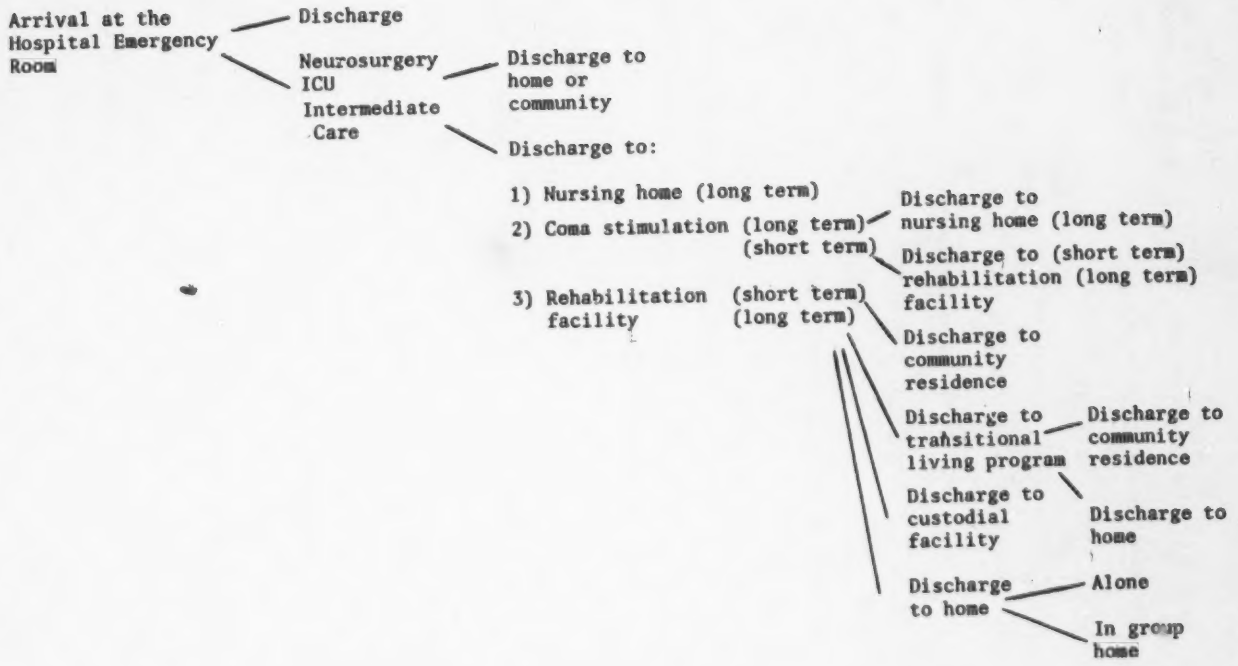
3) implementation of Section 504 of the Rehabilitation Act;

SYSTEM OF CARE

Exhibit I (page 2a) presents a flow chart of "possible outcomes" following traumatic brain injury. The course a person will follow depends upon a huge number of variables including severity of initial insult, age at time of trauma, the absence or presence of alcohol and or drugs at time of trauma, competence of acute medical care, quality of case management and, of course, funding.

EXHIBIT I

Possible Outcomes - Moderate to Severe Head Injury


Arrival at the Hospital Emergency Room
Discharge
Neurosurgery ICU
Intermediate Care
Discharge to home or community
Discharge to:
1) Nursing home (long term)
2) Coma stimulation (long term) (short term)
3) Rehabilitation facility (short term) (long term)
Discharge to nursing home (long term)
Discharge to (short term) rehabilitation (long term) facility
Discharge to community residence
Discharge to transitional living program
Discharge to community residence
Discharge to custodial facility
Discharge to home
Discharge to home
Alone
In group home

The last two factors mentioned - case management and funding are, for many cases, clearly within the creative policy making ability of the Congress.

We have, as a society, built a tangled web of frequently unrelated disincentives and barriers to return to community, incentives for dependence and a piecemeal delivery system with "cracks" wide enough for almost all, except those with the best private insurance, to fall through. Some of the ills of the "system" are willed, some are the result of not having taken an overall view.

For just a peek into the tangled mess of eligibility, disincentive and bureaucratic harassment of disabled persons at its worst one need only look at:

> United States General Accounting Office; Report to the Chairman, Subcommittee on Social Security, Committee on Ways and Means, House of Representatives: Social Security Little Success Achieved in Rehabilitating Disabled Beneficiaries, (GAO/HRD -88-11) December, 1987.

Clearly, there is a silent cultural conspiracy to "pension them off"; move them out of both the fast and slow lanes onto the shoulder to "park" forever. The disabled deserve better. America deserves better.

Such a "solution" cries out for change in the name of justice and civil rights.

The Congress has established a "model rehabilitation system" for spinal cord injured persons. A similar system, driven by a community based ideology, is required for persons who experience

head injury. The spinal cord model has been developed and is in place. The details need not be repeated here because they are so easily available to the Congress.

The second tragedy of head injury occurs in many thousands of cases when the final clinical note reads: "Discharged to home." What the note omits is: "Due to lack of funding." Mandatory catastrophic health insurance in all auto insurance policies would add pennies per policy. The risk pools have already been formed. Yet, for those 25-35,000 persons, the statistical few who will find themselves catastrophically hurt in an auto accident, there will be adequate private sector protection. Such a system of mandated maximum community participation, federal funded model rehabilitation centers, and mandated private insurance combined with mandated seat belts, airbags for drivers and front seat passengers, helmets for bicycle and motorcycle riders, and strict drunk driving laws, could begin to take on the appearance of comprehensive coverage in prevention and rehabilitation for about one half of America's head injured.

Mandated reemployment with the pre-accident employer when and wherever possible in physically and mentally appropriate circumstances in all worker's compensation programs would go a long way toward improving safety and reentering persons to the community. The worker's compensation system should be changed to include mandates that workers be reentered to work not just compensated.

Public funding could then be focused on those persons who are injured due to violence.

One need only then to rethink the tangled web of public assistance programs to more appropriately serve those persons with brain injury who are injured in circumstances other than auto accidents and on-the-job. The Medicaid Home and Community Quality Services Act is a major step in the correct direction.

This past November, the National Institute on Disability and Rehabilitation research held a conference on traumatic brain injury research. The National Head Injury Foundation was very pleased with the outcome of the conference and felt that it will be extremely valuable in advancing services for persons with head injuries. In the very near future, the summary and guide will be published as a result of this conference. This guide will serve as an excellent resource for further research and training of treatment of persons with head injuries.

Senator Harkin and Senator Weicker, your ongoing support over the years to include report language in appropriations bills has been instrumental in addressing the numerous needs and issues affecting persons with head injury. Most importantly, your action has assisted in the creation of the Interagency Head Injury Task Force which has already had one meeting and is planing its second meeting this week. The National Head Injury Foundation is excited about the prospects of this task force and is confident that further advances will be made as a result of its operation. The Foundation also applauds Doctor Murray

Goldstein, with the National Institute on Neurological and Communicative Disorders and Stroke, for his outstanding leadership in research of head trauma and the Interagency Head Injury Task Force.

The Foundation, representing survivors, families, professionals, providers and interested parties such as insurance companies, educational institutions and friends with its deep roots in most of the states, stands to work with you on such a proposal creating a system of care.

IDEOLOGY

> Good intentions, and kind impulses, do not necessarily lead to wise and truly humane measures. Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other and equally important half.
>
> Samuel Gridley Howe quoted in
> Wolf Wolfensberger: Normalization[1]

All of us must ask the question: What is the nature of rehabilitation? and Rehabilitation for what role in society?

Roger LI. Wood has written:

> an unintentional shaping procedure can develop which allows a patient, whilst still in a disoriented, confused or partially conscious state, to gradually associate disruptive behavior with attention from nursing staff (an experience which can have rewarding qualities). Slightly later in recovery, an increase of awareness allows a form of cognitive learning to strengthen the previous associations because the patient begins to realize that there is an increased chance of getting his own way by behaving in a disruptive, intimidating or even directly aggressive manner.[2]

Perhaps, rehabilitation efforts based upon a medical institutional ideology are shaping other detrimental behaviors

and inappropriate self images. A significant proportion of our rehabilitation tax dollars are, in fact, developing dependence not independence.

At some level many people value the traumatic brain injured individual mainly as a consumer, as a "good dependent patient." There is no reason to believe that solely because we have a special relationship to one or many persons who are traumatically brain injured that we, as family or member of Congress, are exempt from major social and cultural aspects of our society; namely, dependence upon the doctor and the doctor dominated medical system.

Wolf Wolfensberger has written:

> When we review history and literature, it becomes apparent that regardless of time or place, certain roles are particularly apt to be thrust upon deviant persons. The way in which these roles transcend time, distance, and culture is remarkable. Most of these socio-historical role perceptions reflect fairly clear-cut prejudices which have little relationship to reality. However, as with many prejudices, the lack of objective verification is not a crucial element in the shaping of a social judgment or social policy. The major roles...include those of the deviant person as a subhuman, a menace, an object of dread, a diseased organism, an object of ridicule, an object of pity, an eternal child, and a holy innocent.3

Only 20 years ago the Atlantic Monthly published a comment that called for "...sacrifice of mentally defective humans, or human vegetables..." to provide organ transplants and "...increase the intellectual betterment of mankind..."4 In 1987 Omni published the following:

> What we decide to do with the life in limbo that is the vegetative state remains to be seen. But it is better to begin to think about it than to ignore the increasing price

> we have to pay for this most unblessed death on the installment plan. (emphasis added)[5]

Ideology defines the "we" and the "they." Dehumanization of the deviant starting with the so-called vegetative state is a reality of our society. Witness the persistence of the medical phrase: "persistent vegetative state" - What does it mean and connote? To Whom? How easy it is to dehumanize a person who has lost "normal " cognitive ability - at birth or through an accident. This is especially easy if we are not careful in what is called the "medical model" of rehabilitation. When the consumer is:

> the
> "sick patient"
> where, after
> "testing"
> and
> "diagnosis", he or she
> is given
> "treatment"
> or
> "therapy"
> by a
> "therapist" and
> who swims in
> "aqua therapy"
> and goes to
> "therapeutic recreation",
> in an environment managed by a
> "doctor"
> in a
> "hospital, SNIF, nursing home,
> or clinic"
> assisted by
> "allied health professionals"
> under state
> "health care regulation" with "case management" and
> "cost containment"
> all leading to
> "restoration, "cure" or
> "discharge."

All belief systems dictate consistent management models and patterns of behavior from facility architecture and interpersonal interaction to hierarchies. The medical model demands segregation and isolation from community because of its convenience for staff and because the consumer is, by definition, "sick." One must ask "Is this the best ideology for the rehabilitation of persons with head injury?" Is it driven by control or liberation? Is it driven by convenience for doctors, administrators and staff or convenience, growth and choice of the consumer?

Our social landscapes are dotted with large institutions that organize people so a few of them can control the vast majority. And it also dotted by individuals who consume the services provided by these institutions.

What we don't need in the year 2,000 is a large leper-like dehabilitating rehabilitation colony dedicated to developing dependence upon large complex professionally dominated rehabilitative service systems. We are in danger of building such a system given current public policy and private sector pursuit of profit.

In head injury rehabilitation a more appropriate ideology would be one based upon the fact that:

- o to be small is to be a truly beautiful facility;
- o community resources should always be the fundamental support structure when and wherever possible;
- o persons who have experienced head injury (and all other

disabled) have civil rights;

o constant support for families and survivors, not supplanting them, is most appropriate; and,

o rehabilitation programs must be dominated by the principle of consent and the dignity of risk.

Public policy must do whatever is necessary to empower persons with head injury to choose for themselves; be it economic, social or political choice. The barriers; institutional, psychological, legal and physical must come down.

Thinking right demands independence and integration into the larger social, economic and political community of choice and risk. These hearings are an excellent beginning. But progress must be made now, before we build a bow wave of impatience, frustration and despair.

SECTION 504

Great progress was made with the passage of the Civil Rights Restoration Act. That step added greater meaning to Section 504.

But, we need not take another decade to learn the lessons of the developmentally disabled. They learn better in regular classrooms without specially trained teachers than they do in a segregated special education environment. We need small personalized facilities without locks, without walls, integrated in every way possible into the larger surrounding community. We need help to integrate those who are isolated at home. This is a civil rights issue. These issues are classic minority issues.

The head injury survivor pays taxes but is denied access to public transportation because the Congress has not mandated access for all citizens. We are told accessible public transportation cost about seven percent more. This is a small price to pay to implement the priceless Bill of Rights. This and other such steps are small dues to demonstrate that all persons are created equal.

The disabled were and are discriminated against by the privileged class. There is at best a two-tier system of health service delivery in this nation. One for the rich and well insured and another for those who are poor or will soon be poor due to catastrophic injury.

We cannot have implementation of Section 504 until the Federal establishment breaks from its pattern, reflective of the larger national social pattern, and takes seriously its committment to civil rights and access. Access to jobs in government and federal contractors; access to hearing rooms in subsidized state and local governments; access to subsidized housing; access to all public accommodations are categorical imperatives easily achieved by the Congress. It is near ludicrous that we can ban smoking in public places, but we deny access to many of these clean air places to some 20 million disabled Americans.

Teeth can be put into Section 504 if the Congress chooses to do so.

Affirmative Action for the American minority that is labeled as disabled is a concept whose time is long over due. The

Congress can translate the concept into a program and require the Executive branch to implement.

SUMMARY

In summary, the Congress has the opportunity to articulate a philosophy of community based resource utilization and reentry during all phases of rehabilitation. It can easily seek opportunities to implement Section 504 rights for all disabled persons in physical access, transportation, employment, housing and education. Finally, the Congress can require the development of funding sources, a "model" rehabilitation system for survivors and rigorous prevention programs to protect the treasury and diminish human suffering.

Thank you.

Sources

1) Wolfensberger - Normalization p.59

2) Roger LI. Wood: p.23

3) Wolfensberger - Normalization p.16

4) Atlantic Monthly October 1967 p.49

5) Omni September 1987 p.117

Senator HARKIN. Dr. Bush, thank you very much for your statement. I have a couple of questions I will follow up on after we hear from the new chairman of the board of the National Head Injury Foundation, Charles Haynes.

I understand this is your first day as chairman, is that right?

Mr. HAYNES. Yes, sir.

Senator HARKIN. We welcome you here. I understand that your daughter sustained a head injury.

Mr. HAYNES. That is correct.

Senator HARKIN. Thank you very much for your taking on this position, this job, and welcome here today. Your statement will be made a part of the record in its entirety. You may begin.

Mr. HAYNES. Thank you.

As the new chairman of the National Head Injury Foundation, as my first official act, I would like to express, on behalf of the board of directors and the executive committee of the Foundation, our deep and sincere appreciation for the opportunity to participate in this hearing, and we thank you for arranging it.

We think it is important. You have heard the previous testifiers explain some of the problems regarding head injury. There is not a great deal I can add to some of the things that they have said, because they have said it so eloquently, particularly Cindy and Sarah Brady and Gerry Bush.

Eight and a half years ago when my daughter was hurt, she was 20 years old, a junior at the University of Texas, on her way back to school after a marvelous weekend at home in November, and for reasons nobody has ever been able to determine, she lost control of her car that November morning on her way back.

The car turned over. She and her friend, who was a passenger, were thrown out of the car. She was knocked unconscious, was picked up and flown to a Medical Center in Houston by helicopter, where there is no doubt she received some of the finest medical care available in the United States at that time.

We had a great neurosurgeon and other great surgeons who worked with her, and they did a good job. They saved her life. But at the end of 90 days, we were told, "You are going to have to do something different. You are going to have to move her out of this hospital. We need the bed."

We were totally flabbergasted. We said, "What do we do?" "The advice was I will give you the name of three nursing homes. If you select the third one, which I recommend, she will be dead in a month, and that will probably be the best thing." For a parent, that is a terrible blow.

We took the news as calmly as parents could, except that my wife started to say, "There must be other alternatives," and the surgeon said, "No, not that I know of." And she started to protest again and say, "Well, I heard . . ." And his advice to her was to quit listening to the gossip in the halls and quit reading the miracle cures in the Reader's Digest, because there were no miracle cures.

We were lucky. We walked out of that doctor's office and down the hall in the hospital, and a very young, just beginning social worker, who was afraid almost to interfere or intrude on our sorrow, stopped and said, "I don't want to intrude, but I have

heard of a hospital that is beginning to treat head-injured patients."

We obviously called the hospital. We transferred our daughter there within 24 hours. That hospital was beginning to do some work with the head injured. They were taking comatose patients. We transferred her there and fortunately, she didn't die. We didn't let her die.

She did come out of the coma. She is what they have said, and we, for many years have said, a miracle case. I have discovered since that there are a lot of those miracle cases out there. She is by no means unique.

She did wake up after 90 days in a coma. Nobody explained to me that she wouldn't walk out of that hospital. I naively thought that if she woke up, we would ultimately walk out of there and pick up our lives again.

That didn't happen. That doesn't happen. That is not the way it is.

But there was no group, no organization, no support, nobody to explain that to us or to sit down and talk to us at the time. The Head Injury Foundation did not exist.

Later on we had the opportunity to begin to talk to other parents, and they were being faced with the same thing. Fortunately, Marilyn Spivack and her friends in Boston had faced similar situations and had gotten a group together which ultimately became the National Head Injury Foundation, and we began to do the same thing in Texas, and ultimately we grew together.

The tragedy is the advice we were being given really wasn't true, because there was a lot of work being done, and there is still a lot of work being done.

Today, Bonnie lives alone in her own apartment. She certainly has some handicaps. She has a voice problem with one paralyzed vocal cord. She walks with a limp. But she lives a relatively independent life, but it is not independent enough that she could survive or live alone without some type of support system.

Fortunately, she has that support system in her mother, who manages, behind the scenes, her life for her. So it is semi-independent, but I share Sarah Brady's concern, and Cindy's concern, and Gerry's concern, "what is going to happen to her when we are no longer here?"

There is no system available to take care of her. Over the last nine years, acute rehabilitation facilities have proliferated. I doubt if there is any situation—I hope that no family in the future is ever told there is no hope, there is no alternative. There is hope and there are alternatives.

The rehabilitation facilities have now expanded into outpatient programs and transitional living programs, but we still have no long-term system of care. That, to me, is what we need to focus on in this country.

We have come a long way. We have made a great deal of progress. We have scarcely scratched the surface of the need.

I could go on, but I think I have probably used my time.

[The prepared statement of Mr. Haynes follows:]

Testimony of

Charles W. Haynes
Chairman, National Head In jury Foundation

Before the Committee on Labor and Human Resources,
Subcommittee on the Handicapped

TESTIMONY OF CHARLES W. HAYNES

Eight and a half years ago, when my twenty year old daughter was hurt on her way back to school at the University of Texas in an automobile accident that left her unconscious and comatose for nearly ninety days, so little was known about head injury rehabilitation - or its potential - that our surgeon, who had worked so hard to save her life in the emergency room, advised us to transfer her to a nursing home and let her die. He went on to explain that she was not likely to come out of the coma and even if she did she would have to spend the rest of her life in a nursing home. When my wife asked him if there weren't some other alternatives, he said "not that I know of" and when she started to protest he said we would be better off to stop reading the "Reader's Digest" - there were no miracle cures.

It is impossible to describe the anguish and heartbreak that kind of news can do to a family. To be given no hope, no encouragement, no alternatives is a devastating experience and the tragedy is that it wasn't true. In those days - less than ten years ago - there was no head injury foundation, no support group, no information, no literature available, no place to get any information. There was, however, a very young new social worker on the floor who hesitatingly told us that she had recently heard of a hospital in the area that was beginning to do some work in the field of head injury.

We have come a long way since that day in January of 1980. Bonnie didn't go to a nursing home and we didn't let her die. We found the hospital which was beginning to work with head injured patients. By today's standards the treatment whe received would be considered outdated and obsolete, but all of a sudden there was hope and we had encouragement.

Today, she lives alone in her own apartment, does volunteer work at a local hospital and works in my office where she does word processing, payroll and other computer related activities. This is not to say that she has "recovered" to that happy carefree college coed that she was before, but neither is she so severely physically handicapped that she requires supervision or is a burden on society. She walks with a limp and one arm is partially paralyzed as is one vocal chord.

It is the difficulty with her memory and the cognitive deficits which prevent her from leading an active life with friends and social opportunities.

In many respects Bonnie is one of the lucky ones because she did get acute rehabilitation in the early stages and our insurance was sufficient to cover her medical bills for the first year and lucky that we happened to learn of a hospital beginning to do rehabilitation. I am still afraid to think of what the consequences might have been had we followed the neurosurgeon's recommendation or if the young social work had not intervened.

Other families in other parts of the country were experiencing similar situations so that out of the frustration, anger and desperation of families across the nation the National Head Injury Foundation and its state chapters were born. Today it would be grounds for a malpractice suit if any physician or surgeon told a family there was no hope, or no imformation, or no rehabilitation facility to work with the patient.

We have come a long way, but we have hardly scratched the surface of the need. Others today will tell you about the size

of the problem, the epidemiology, the proliferation of facilities and treatment modalities, some of the promising areas of research and the expansion of the activities of the Head Injury Foundation. I would like to take a moment to call your attention to another area which thus far has been essentially ignored. That is the concern for the special problems relating to traumatic brain injury in infants and children. Thus far little or no attention has been paid to this age group even though the incidence of head injuries in childhood has been estimated at approximately one million per year or at a rate of 200 per 100,000 children. The etiology of TBI in childhood may vary from those related to motor vehicle accidents, falls and other accidental injuries, to those subsequent to violence or abuse, the so-called "non-accidental" traumatic brain injury.

Because of the mandated educational programming for all handicapped children (P.L. 94-142) and the extensive range of available special education services from very severe/profound to mainstream programs, potential help can be available when the research is completed which will provide the body of knowledge necessary to develop programs specifically for the special needs unique to Traumatic Brain Injury in infants and children.

General areas of specific research should include:

- -effects of TBI when sustained at different developmental periods and the relationship of age at injury to speed of recovery.
- -effects of non-accidental trauma and how they differ from accidental trauma.
- -the impact, both short and long term, of mild and moderate injuries and their subsequent effect on behavior.

-effects of TBI on cognitive processes and learning ability in children.
-how can educational personnel be most effectively taught to manage the needs of children after TBI.
-are there children who are at high risk for TBI, and if so, how can they be identified and what techniques could be used to prevent TBI.
-effects on the family, including the parents and siblings, of having a child with TBI and how to reduce family stress and encourage coping.

One thing is already clear and according to Dr. Ellen Lehr, a leading researcher in pedicatric TBI, infants and children are not simply small adults. The same guidelines will just not serve the purpose.

To summarize, modern medical science and technology has made great strides in saving the lives of those who have suffered a head injury, but in so doing have created an entirely new disability group, composed primarily of children and young adults who once they become stabilized medically will live a normal life span of years. Their handicaps, however, cannot only be physically severe but also mentally incapacitating. They suffer the worst of both worlds. As concerned members of society it seems to me that we have an obligation to provide the resources necessary to improve their quality of life and help them become productive members of our society.

Senator HARKIN. You have used your time well, very well.

Mr. HAYNES. Thank you.

Senator HARKIN. All three of you have just added tremendously to my knowledge and my own determination to make sure that we just do not let this thing end here, that we move ahead and really do something.

I have got to admit to you I do not know that I have all the answers, I do not. I know some of the directions we have got to go, to try and get all these pieces put together. I guess there are just a lot of different pieces.

Dr. Bush, you talked about Section 504. 504 is very important. 504 only goes to recipients of Federal dollars. As you know, in 1964, we passed a Civil Rights Act in this country, the Civil Rights Act of 1964, which stated that no one can discriminate on the basis of race, religion, sex, and national origin.

We all agree that this was a major step forward for America, and we all are a better society for it, a much better society. Here it is, 25 years later, and yet there is still a group of people in our society to whom the courthouse doors are still closed.

You see, all the Civil Rights Act did was open the courthouse doors. You still have to prove your case, but at least it opened the courthouse doors. But there is a group, disabled Americans, to whom the courthouse door is still closed.

Senator Weicker and I will soon be introducing legislation that will address that missing element, to extend the Civil Rights Act of 1964 to all persons with disabilities in our society. That is one of the pieces, just one.

There is so much more in terms of family support. I mean, it is important that these individuals have that love and that support of their families. Where do the families go to get support? It is a terrible burden, not only financially, but emotionally and everything else.

I know the Federal Government cannot do everything, but by gosh, I believe, as Senator Weicker said, this really is a test of our society and what kind of society we are.

We have proven that we are a society that cares through the medical advances that we have made in saving these lives, but to just save a life and then say our obligation is over with, I think it is just immoral to say that. We not only have to say we are going to save lives, but we are going to make those lives whole, to do something.

I said this morning in my remarks that I believe there is a role for the Federal Government, a definite role. Again, with your wise counsel, and the counsel of the Head Injury Foundation working with us in the ensuing months, I hope we can begin to make those steps and put together the kind of package that we need to get people to understand what we are talking about.

Until Marilyn Spivack and other people started talking to me about traumatic brain injury, I had no concept of what we are talking about. It never occurred to me how many people we were talking about. How many did you say, 700,000?

Dr. BUSH. 750,000 will be head injured between now and the end of the year in the United States, and of those, about 40,000 will be

moderate to severe, meaning they will never return to the same level of social and economic activity as prior to the trauma.

These numbers make any other condition look small. Head injury kills more people under the age of 34 than all other conditions combined. And under 44 it kills more than any single condition.

When we see this billion for cancer—which may be appropriate, that you appropriate annually—this is the old people's disease, heart, stroke, this is the old people's disease, and not to be uncompassionate to them, but the young are dying of head injury. And the young persons with head injury are living longer and longer and longer.

Patrick will live for 50 to 75 years. He has a normal life expectancy. So, unfortunately, do his parents, which means we will go before he will, and I do not want him in a county home somewhere, or a Federal institution, some form of leper colony that we have created in the late 20th century.

I want him in the community. I want the American with Disabilities Act desperately. We are not trying to get from the back of the bus to the front. We are trying to get on the bus which Patrick's taxes help pay for.

Senator HARKIN. That is right.

Dr. BUSH. And he is taxed, but he cannot get on the bus, nor can thousands of other disabled. We are not trying to get him a job where he has career ladders and can compete. We are trying to get him into the employment office, but he can't get through the door, because of our insensitivity as a society.

The Senator is correct. This is the measure of civilization.

Senator HARKIN. Cindy, you talked about your mother, you live with your mother.

Ms. MULVEY. Right.

Senator HARKIN. Your father passed away some years ago. I can only assume that the support of your mother has just been invaluable, right?

Ms. MULVEY. Pardon?

Senator HARKIN. The support of your mother and your family has been something that you really needed and you have relied on.

Ms. MULVEY. Well, financially, thankfully, I settled my lawsuit and I have got that for now, and I was covered under my mother's insurance, when my accident happened. So they paid all the medical bills. There are many people that are not that fortunate and they need more—many, many people—need more help.

I need more help. I need something in the afternoons more fulfilling, because Stop and Stop, I do the job because it is a job. It is not fulfilling at all to me.

The only reason I like it is to talk to the people that come in. It is not for me. I need something more fulfilling.

Senator HARKIN. Again, I just say to all of you that the more I think about this, the broad array of things that are needed, I think perhaps our approach is too segmented. When we look at the segmented little items, we do not put them together in a package.

Because of the extensive nature of head trauma in our country today, we just cannot just look at air bags and seat belts as air bags and seat belts. That is the way I have thought of it. My daughter

who is age 11, is now riding a bike, and I am thinking, my gosh, I have not made her put on a helmet yet; but I can tell you something, she is going to be wearing one now.

Dr. BUSH. We will all come and visit her, Senator.

[Applause.]

Dr. BUSH. Senator Metzenbaum feels the same way about bicycle helmets. I think he has about 400 more than he needs. He might lend you one, Senator.

Senator HARKIN. You do not often think about these things. We need a continuum of approaches. I will tell you my own State of Iowa passed a law mandating helmets for motorcycle riders, and there was such a wave of protests, that they took the law off the books again.

I met one person in a hospital in Iowa one time, just one time, who had a head injury from a motorcycle, and that settled it for me right there.

This is an issue that goes beyond the individual's own desire for the freedom of sitting on a motorcycle; that person who is sitting in that hospital is taking from all of us to support him.

I do not deny that we should not provide that care. All we ask in return is that care and prevention take place in the beginning. This whole continuum of things, seat belts, helmets, air bags, and then the medical services, the rehabilitation services, the support services, and the long-term care; all need to be focused on this thing together.

I am beginning to see perhaps a support group out there now that has been sensitized and now is alert to this, and perhaps now we can really make some things happen. I hope so.

Mr. HAYNES. We certainly need it.

Senator HARKIN. Thank you all very much.

Dr. BUSH. Thank you, Senator. We really appreciate your concern, your attention, your love, and your help.

Senator HARKIN. Thank you very much.

Mr. HAYNES. And we are always available, any assistance that we can give you.

Senator HARKIN. Do not worry, you are going to hear from me. We are going to call on you.

Thank you all very much. Cindy, thank you.

As usual, I am now under a time limit here. I would like to call our third panel, Dr. Howard Katz and Dr. Walter Verduyn.

On the third panel is Dr. Howard Katz, a physician who specializes in the treatment of persons with head injuries. I had the privilege and honor of meeting him earlier today. Dr. Katz will present testimony on gaps in education and rehabilitation services for children who have suffered head injuries and on what needs to be done to fill those gaps.

We will also hear from Dr. Walter Verduyn, a respected physician from Waterloo, Iowa, who is a leader in the area of rehabilitation of persons with traumatic brain injury and a member of the board of directors of the Iowa Head Injury Foundation.

Dr. Verduyn will also discuss the service delivery system, particularly with respect to adult survivors of head injury. I am calling on Dr. Verduyn to go first.

Dr. Verduyn, welcome. Your statement will be made a part of the record in its entirety. I read your statement last night, as I did Dr. Katz'; both are excellent.

I just say that if you will please summarize, I would be most appreciative.

STATEMENTS OF WALTER VERDUYN, M.D., COVENANT MEDICAL CENTER, WATERLOO, IA, AND HOWARD KATZ, M.D., CHIEF OF HEAD INJURY SERVICE, MISSISSIPPI METHODIST REHABILITATION CENTER, JACKSON, MI

Dr. VERDUYN. I came to Iowa from the Netherlands in 1960 as a refugee from Southeast Asia. Being here makes me feel a citizen of the United States and I am proud to be from Iowa.

I also bicycle. I have ridden "RAGBRAI" 14 out of 15 times and I do wear a helmet. It is a bicycle ride which involves about 8,000 people who have moved from western Iowa to eastern Iowa every year. It is interesting. It has been called "Woodstock on Wheels."

I have been involved in head injury care for about 15 years and I am here partially because I am extremely frustrated in trying to provide and arrange the care that I see is needed, and I find it very difficult.

In my opinion, there is no recovery from traumatic brain injury. There is much improvement, but people do not really recover to their preinjury status.

If brain-injured people do not receive rehabilitation at an early time and are not challenged appropriately, they will not learn appropriately. In fact, we find if they are placed in the wrong environment, they acquire poor behavior which is very difficult to change later.

The life expectancy, as Dr. Bush said, is normal, which means for a 20-year-old, we are going to provide care, one way or the other, for at least 50 years.

Head injuries are not a new phenomenon. Ever since man hit other men on their head with a club or stone, we have had head injuries. They have become a problem, as we know, in the last years, but looking through the literature, the phenomenon that we see today have been described back to 1900 and before then. It is not necessarily new.

I would like to read into my testimony the definition as is used by the National Head Injury Foundation.

> Traumatic head injury is an insult to the brain, not of a degenerative or congenital nature, but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment.

If you will note, it said nothing about being unconscious. You do not have to be unconscious to sustain traumatic head injury. I have a son who was injured in football, was not unconscious, who shows all these behavioral changes. It took me six years to diagnose it.

I did not know what was happening to that kid until I finally put the pieces together.

Of greater concern is the lack of insurance. We have 35 million people in this country that have no health insurance. Catastrophic

health insurance will help, but it does definitely need to include rehabilitation.

I have a few patients who come from other parts of the country that have no-fault car insurance. That is very helpful.

If there is insurance, it is quite often that it excludes rehabilitation. I recently had two people that had fine insurance, but it did not pay for rehabilitation. The HMO's, that have become very popular, to save cost, often exclude rehabilitation, or limit it severely.

In my community, I have to ask for precertification on rehabilitation patients they often have very limited stays, and I'm required to send them a report every week, and this is for patients who are going to be with me for three to six months.

If they do leave the hospital and need outpatient care, they usually get paid only physical therapy and only 60 treatments, no speech, no OT, no counseling for themselves or their families.

The other struggle is the definition of progress by insurance companies, agencies, and review organizations. What is progress? I recently testified for a hearing on a Title XIX case, where some of the services were denied because there was no progress. They were looking at weekly, or monthly, or three-month progress.

I had followed that patient for four years. He went from a Level II on the cognitive scale to a Level VI, and we have eight levels. So he made significant improvements.

Another problem that we see is that these people have no insurance. They need to have Social Security before they can get Title XIX. I have a letter from Rosie Wilhelm, the social worker at the University Hospitals. Patients are put on medical hold for three months, until the Title XIX comes through, and then they can be transferred to rehabilitation.

In the meantime, they are laying or sitting in a very expensive university hospital, not getting rehabilitation.

Another problem, and I am aware of three of my patients, who although they are U.S. citizens, are displaced persons. One young man was injured in Texas, married to a woman from Alaska, was born and raised in Iowa, and was discharged from the military service in Texas where he sustained his injury.

The local county would not assume any responsibility. His parents were born and raised in Black Hawk County, raised six children there, both worked and paid taxes.

Another young man was raised in Iowa and had just moved to Colorado. He is not eligible for support in Iowa.

A third one was from Michigan, lived in Arizona where he had his accident. His wife brought him back to Iowa.

Essentially, they are displaced persons.

I would like to return to problems with insurances. I have a young man—actually a child—about seven years old who was injured by a car as a pedestrian when he was three years old, was in the hospital for acute care for four weeks, was sent home without rehabilitation.

He came in my office about two months ago. We evaluated him. We feel he needs brain injury rehabilitation. He is fortunate to have health insurance, which manages who they will admit to a hospital. I would not talk about this case, but Saturday I was in my office, and found a denial for the hospital admission because there

was no medical necessity for him to be admitted to a rehabilitation department.

His family went bankrupt during the recent depression in Iowa, which, by the way, still exists. They scraped to keep their health insurance in force. The insurance won't pay.

I have followed a young woman—she is about 15 now—since the age of three, actually followed her intermittently. She was quite severely disabled, was placed in a care facility where she was placed with the profound and severely mentally retarded. This young girl learned very rapidly very bad behavior.

She has been in about 25 facilities over the last 10 years. We are paying now $16,000 a month in an out-of-state facility where she gets an education and where her behavior is managed.

Regulations require three hours of therapy for a patient in a rehabilitation department. We get patients emaciated, weak, not being able to do anything, that cannot tolerate three hours. I accept them and I constantly argue with my own staff and administration. If you leave these people in an acute hospital, they are not going to get stronger, they are not going to get better.

We need to move from post-acute hospital or post-acute rehab, we like people to go home or sometimes they need to go to a nursing home. They are nonresponsive, they need care. My social worker and rehab counselors have placed 70 to 80 phone calls to different facilities throughout the State.

Patients appear to be unwanted, still living organisms, for which society only has an interest to place him or her in a warehouse for the rest of their life, for their life expectancy, which can be up to 40, 50 years.

I have a paper from the Task Force on Lifelong Needs, and it includes some basic assumptions. I have added that to my written presentation. It is assumed that each person has a natural drive toward productivity and self-determination.

Each person seeking assistance has a need and some capacity for self-direction and self-determination. I won't read the whole paper, but it points out some of the issues.

I would like to close. We need better understanding of the disability caused by traumatic brain injuries. We need better prevention—seat belts for all people in cars, in buses, airplanes we don't have to argue about. People put them on.

We need better health insurance. We need better alternate fundings. It is very ironic that quite often the money is there, but the patient doesn't fit the qualifications and then the monies are not disbursed.

The insurance agencies, the Government agencies need to be flexible enough to say this particular program makes more sense, we will pay for it, and that often does not happen.

Incidentally, I also care for respiratory-dependent quadriplegics. I have a young man right now who is a second year student at the University of Iowa, who makes straight A's in electrical engineering. He was initially turned down by vocational rehabilitation because he had no vocational potential.

We need better continuing care. We need better systems of care, and the integration of those systems is needed. And particularly,

the patients need better access to these systems. They often cannot get in because they do not have the funding.

There are good systems available. They are very expensive. And like we said, most people have no insurance. We need better trained health professionals.

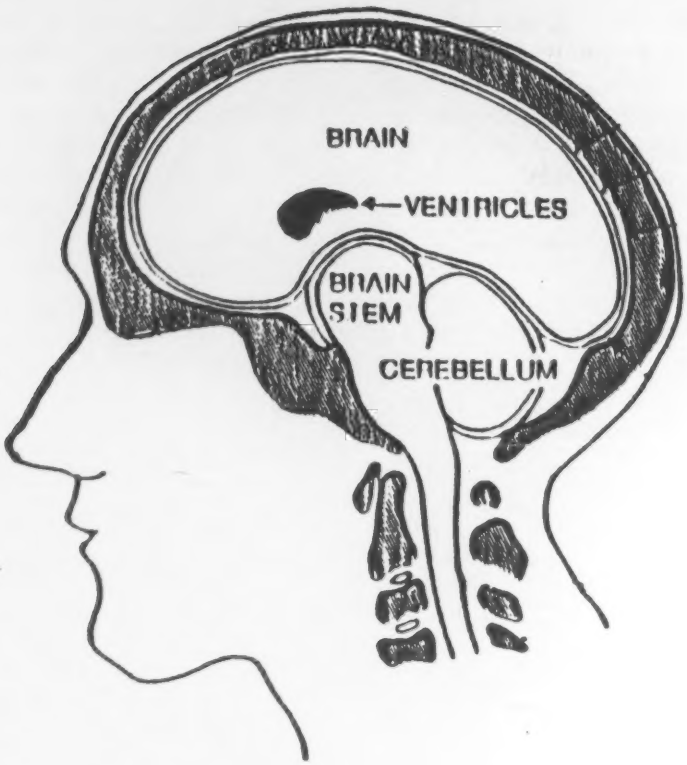
My frustration at this time is that as we do better, we see more patients. I currently see about 100 to 120 head injured a year. It gets very frustrating. The stories are very much the same. The struggles are very much the same. You run into the same difficult rules that you cannot get around.

And it is not only physicians; it is the nonphysicians in the health system, it is the social workers, it is the agencies, and it includes the educators, and we are really interested in a better quality of life.

Thank you.

[The prepared statement of Dr. Verduyn follows:]

"LONG-TERM CARE NEEDS OF HEAD INJURED"



PRESENTED BY:
W.H. VERDUYN, M.D.
MEDICAL DIRECTOR OF REHABILITATION
COVENANT REHABILITATION CENTER
COVENANT MEDICAL CENTER
WATERLOO, IOWA 50702

TO:
SENATE SUBCOMMITTEE ON THE HANDICAPPED
HEARING ON TRAUMATIC BRAIN INJURY
APRIL 12, 1988
2:00 pm
SD-430
DIRKSEN SENATE OFFICE BUILDING

COMMENTS IN REGARD TO ACUTE CARE, LONG TERM CARE, REHABILITATION AND EDUCATION FOR TRAUMATICALLY BRAIN INJURED INDIVIDUALS IN RURAL AREAS BUT SPECIFICALLY AS IT RELATES TO IOWA

I immigrated from the Netherlands directly to Iowa in 1960. Prior to my high school education and medical school in the Netherlands, I had lived in Indonesia where I spent three and a half years as a child in a Japanese war camp.

In October 1961, I started practice in Reinbeck, Iowa, in general practice. I became board certified in family practice and did develop an interest in long term care of patients. I started seeing severely head injured people in approximately 1974 and after a Fellowship at Craig Rehabilitation Hospital in Denver, Colorado, 1976-77, my practice gradually concentrated itself completely on the care of individuals receiving trauma to the central nervous system which includes brain injuries and spinal cord injuries.

I am co-author of the textbook for vocational rehabilitation counselors called T.B.I. (Traumatically Brain Injured).

I was instrumental in the development of the Iowa Head Injury Association in 1979. I have been a board member of the National Head Injury Foundation in its early years and am currently a member of the Professional Council and the Provider's Council. I have also participated in the Governor's Task Force on long term care. I was a member of the Commission For Accreditation of Rehab Facilities Task Force that developed standards for acute rehabilitation and long term rehabilitation of traumatic brain injury patients.

I currently am a surveyor for the Commission For Accreditation of Rehab Facilities for brain injury and spinal cord injury rehabilitation programs.

Over the last 15 years, I have seen over 600 head injured individuals. I have one son who sustained a so called "minor head injury" as a junior in high school.

NHIF definition of traumatic head injury is as follows. "Traumatic head injury is an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning. It can also result in a disturbance of behavioral and emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment."

The magnitude of problems related to traumatic brain injury is staggering. One of the reasons for the rapid growth of this population is the improved medical services from emergency services through surgery and acute care services.

Although the comparison is difficult to make, the issue of AIDS and the fear that our population has of AIDS is significant. To look at the numbers for Iowa according to the latest information, Iowa has identified 54 AIDS patients.

Last year, the central registry for brain and spinal cord injury was passed and we are now registering almost all head injured individuals in the state of Iowa through this system. The projections at this time are 10,000 head injured individuals in Iowa annually. Although many of these people will not have significant problems, a great number of them will. In the past, our estimates were at least 600 severely injured in the state of Iowa and many so called minor head injuries with behavior and cognitive problems.

There are currently 35 million Americans that have no health insurance, tens of millions have insurance so inadequate that a major illness or injury leads to bankruptcy or inadequate care.

One of the major problems at this time is the lack of health insurance for many of the individuals that have sustained severe head injuries because the majority of these people are young who are often not covered by their parents insurance anymore and have not obtained sufficient employment time to receive insurance through their employers. Even if people have insurance through their employers, it frequently is through an HMO type of organization. This creates a whole new set of problems which causes inadequate care and rehabilitation of the traumatically brain injured people.

In addition, there is significant lack of proper facilities for continuing rehabilitative care, especially after acute hospital rehabilitation, especially when no funding is available.

Another pressing issue is the lack of properly trained personnel which includes physicians who do not understand their patients rehabilitation needs and possibilities.

Since many of the brain injured individuals have multiple problems varying from behavior to emotional to physical problems, they often are placed in inappropriate environments such as psychiatric facilities, which are not equipped to deal with the traumatically brain injured individual. Another major problem in providing proper care are the regulating agencies who have developed a maze of often contradictory regulations to provide the care for people. This includes agencies that monitor patient care that have inappropriate standards to measure the care needs for tramatically brain injured patients. This includes the committees reviewing the medical charts that often include physicians who have no training or experience in the long term management and rehabilitation of traumatically brain injured people.

Since many of the brain injured individuals are children, it has become obvious that the school systems are not equipped to provide proper education for this category of students.

It is obvious that we do not have a proper system of care; acute, sub-acute, long term, and lifetime for people with acquired disabilities due to traumatic brain injuries.

Due to our improved acute health care system, the great majority of the brain injured individuals will survive their injury. Once they do survive their injury, there is a good chance that they will also survive an average life expectancy, which for a 20 year old, will be at least another 50 years. With that in mind, it behooves us as a society to spend the funds for effective rehabilitation in the early stages after the head injury rather than provide lifetime care at inappropriate levels in inappropriate institutions.

Another great concern of mine is for the family members of the brain injured individual. The traumatic impact on these family members is devastating. They too have great needs. Their needs are in support and counseling and sufficient funds to survive economically as a family in addition to having to survive emotionally as a family.

Crucial long term family counseling and support is usually not covered under health insurance specifically not under HMO and similar programs.

Unless our society is willing to provide the initial funds needed to allow our head injured individuals to become functional members of our society, it might be more appropriate to not provide the acute emergency services and acute medical care. In many cases, we have seen $200,000 spent on acute medical care but then no moneys available for their rehabilitation and appropriate long term management. This is a travesty!

Funding appears to be the most crucial issue for many of the head injured.

I am aware of efforts to provide catastrophic insurance. This type of insurance will need to specifically include long term rehabilitation for the traumatically brain injured and spinal cord injured patients. At this time the feeling of the rehab professionals is that the catastrophic insurance will be used up for acute care and there still won't be funds available for long term care.

The difficulty with the current health insurers especially HMO's is the definition of progress as is applied by the insurers and the regulating agencies. The "progress" of head injured individuals is often slow and will totally stop if rehabilitation efforts are halted. To illustrate some of the problems we are facing, I will summarize a case history. One of my patients was injured due to gunshot wound to the head at age 13. He initially received his care in an acute care facility of a major hospital.

He was transferred to our rehabilitation department for rehabilitation and at the time did not appear to be responsive. His level on the cognitive scale was estimated as a Level I. This young man was essentially nonresponsive. After extensive period of rehabilitation, he had advanced to a Level III. Although we wanted to continue the rehabilitation in our hospital, the third party payer indicated that they felt he did not need any further hospital rehabilitation.

We suggested transfer to a local facility at a nursing home which was developing a brain injury program. The facility did not have a skilled nursing classification and the insurer would not pay for his stay. The insurer was willing to send this patient to a facility on the East coast that was properly licensed where the fee was higher than in our acute hospital rehabilitation setting.

After a year to a year and a half, the insurance funds were almost exhausted and the patient was transferred to our community where he was placed in a skilled nursing facility which was just starting to develop a brain injury program. The funds were quickly exhausted and patient became eligible for Title 19.

The foundation that provides the review for Title 19 Skilled Nursing indicated that in their opinion this patient was not making sufficient progress to stay in a skilled nursing facility.

Eventually this case came to hearing where I testified that this young man over a period of three to four years had made progress from a Cognitive Level I to a Cognitive Level VI. The cognitive scale also known as the Rancho Los Amigos Cognitive Scale runs from a Level I to Level VIII. In addition to his cognitive problems, this young man also has significant physical problems. He has progressed from needing all feedings through a gastrostomy feeding tube to now being able to take part of his food by mouth. In addition, he has developed enough function in one arm that the staff is in the process of teaching him to feed himself.

It is even of more importance to note that this young man is able to work with a computer and communicate by using the computer.

If this young man had not been caught in the web of regulations and funding tied to regulations, the insurance funds would have lasted much longer and he would have received more appropriate continuous rehabilitation with the eventual outcome of being a person functioning at a higher level at much less long term cost.

The difficulties with the health maintenance organization is even more significant in that they attempt to save costs by denying or severely restricting rehabilitation. Most HMO's do not provide for long term care after hospitalization and provide only very limited outpatient rehabilitation often only limited to physical therapy while most head injured individuals need intensive occupational therapy, speech therapy, and counseling support. The HMO in my community has excluded me from automatic admissions of their patients to rehabilitation unless I have received prior approval. This does not apply to any other physicians in the community although they do not have any experience or training in this specialized field. In addition, I am required to send weekly reports on these patients who will generally be receiving rehabilitation for at least three to four months. As part of the regulations, rehabilitation programs produce at least bi-weekly reports that are available to third party payers.

Most of the HMO's have a board of physicians that review the needs of the patients. The field of rehabilitation is relatively new, especially the field of brain injury rehabilitation which has developed over the last 10 years is essentially unknown to most physicians.

Although I have developed a new program at Covenant Medical Center over the last 13 years, physicians and other medical professionals are still surprised when we inform them that we take nonresponsive, comatose patients for rehabilitation and that many of them wake up and a good number of them walk out of our facility.

It is very frustrating to receive referrals late six months or longer after an injury and have to attempt to resolve all the complications that developed during the well meaning but inappropriate long term stays in acute hospitals or long term care facilities.

We at this time totally lack a system of care for head injured individuals. Our rehabilitation counselors and social workers make 70 to 80 phone calls to care facilities for placement of our patients. For any number of reasons again, a mixture of funding problems and regulatory requirements make it impossible for many facilities to take patients. The attempt to place these individuals is very degrading to the counselor/social worker as well as to the patient who appears to be an unwanted, still living organism for which society only has an interest to place him or her in a warehouse to remain for the rest of their life expectancy which can be 40 to 50 years.

For those of us working in this field in the rural, non-metropolitan areas, our time is spent on patient care. Due to the tremendous work load, most of us do not have the time nor the energy to be able to change the system. There is a need for extensive grant money for those of us working in this area. This money should be provided to brain injury rehabilitation programs with extensive experience in brain injury rehabilitation located in relatively rural areas.

This money is needed to develop good, acute rehabilitation in hospitals with related systems of brain injury rehabilitation and long term care centers specifically for head injuries; transitional homes, vocational programs, and permanent living facilities all geared to the brain injured individual with integration into society.

The funds are also needed to develop support systems for the head injured and their families that are at home, back in school, or at work. Brain injury rehab is a lifetime process. Many brain injured patients and their families need support and assistance at different times in their lives by people who understand the difficulties. These funds should be available to the head injury support groups and agencies that can develop and provide the needed support.

Significant funding is needed to train professionals, medical as well as educators and agency personnel. Teaching can be done on a local level. My staff and myself do numerous presentations but there is a limit to our energy since we need to spend our time with our patients.

There is a special need for traumatic brain injured children. The schools are generally unable to provide proper education because traumatic brain injury is not a recognized disability. The categories are mental retardation, learning disability (attention deficit disorder), emotionally disturbed, and physically disabled.

Traumatically brain injured children often have features of all of these but do not fit a specific category and are often inappropriately placed in a disability category or in the regular school because they do not seem disabled but have significant cognitive and behavior changes which makes participation without support in school almost impossible.

Brain injured people and children can learn good as well as bad behavior. Trying to undo acquired bad behavior in children is difficult and expensive, currently costing $13,000 to $16,000 a month and is not available in Iowa.

PRESENTATION - Page 6

INSURANCE PROBLEMS

Relative to many of the insurances, particularly HMO, would be innovative payment for appropriate levels of care even if this means going outside the contract. We often see inappropriate care paid for because it is part of the contract while appropriate care does not receive approval.

Payment for long term managed care in the most appropriate facility nearest to home to maintain as much as family involvement as possible.

If managed appropriate care is at home, in an outpatient program, or at school, there is also a great need to provide respite care for families.

It is essential to provide funding for the educational system for the special educational needs of the brain injured child. These children should not be included with mentally retarded, developmental disabled, behavior problems, or physically disabled although they have features of all of these.

The funding needs to be available to hire appropriately trained people, not necessarily licensed practical nurses or registered nurses.

If professional care is needed and provided, the professionals providing this need to be trained in the care and management of brain injured individuals. Just having a degree does not mean they have the proper background to provide care for brain injured individuals.

There is a tremendous need for long term follow up. This does include seeing the patient, checking on physical and cognitive problems, or behavior problems. Included in this should be social evaluations, how the family is doing, etc. If needed, care should be able to be provided which might be as little as talking to an employer or providing the proper supportive counseling for the patient and their families. Generally, this kind of care is not available through any of the systems of funding that we currently have or do not have.

NATIONAL HEAD INJURY FOUNDATION
TRAUMATIC HEAD INJURY DEFINITION

Traumatic head injury is an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminshed or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment.

MEASURES OF COGNITIVE FUNCTIONING IN THE REHABILITATION FACILITY

The Levels of Cognitive Functioning Scale* developed by the head injury treatment team at the Rancho Los Amigos Hospital in California is very useful both to therapists and to families to help understand the behavior of each individual as he goes through rehabilitation. These levels apply specifically to head-injured people in the first weeks or months following injury and should not be used years later as a gauge of improvement. Initially, progress will be rapid and you will notice your loved one moving from Level II to Level IV and V. As the months go by, progress slows, and at some point the individual will seem to "plateau" perhaps at Level VI or VII. The level at which this will happen cannot be predicted ahead of time. The Rancho Levels reproduced as follows are much shortened but still provide some insight into the expected progression during rehabilitation.

I. **NO RESPONSE:** Unresponsive to any stimulus.

II **GENERALIZED RESPONSE**: Limited, inconsistent, non-purposeful responses, often to pain only.

III. **LOCALIZED RESPONSE**: Purposeful responses; may follow simple commands; may focus on presented objects.

IV. **CONFUSED, AGITATED**: Heightened state of activity; confusion, disorientation; aggressive behavior; unable to do self-care; unaware of present events; agitation appears related to internal confusion.

V. **CONFUSED, INAPPROPRIATE, NON-AGITATED**: Appears alert; responds to commands; distractable; does not concentrate on task; agitated responses to external stimuli; verbally inappropriate; does not learn new information.

VI. **CONFUSED APPROPRIATE**: Good directed behavior, needs cueing; can relearn old skills as Activities of Daily Living (ADL); serious memory problems; some awareness of self and others.

VII. **AUTOMATIC APPROPRIATE**: Robot-like appropriate behavior, minimal confusion; shallow recall; poor insight into condition; initiates tasks but needs structure; poor judgement, problem-solving and planning skills.

VIII. **PURPOSEFUL APPROPRIATE**: Alert, orientated; recalls and integrates past events; learns new activities and can continue without supervision; independent in home and living skills; capable of driving; defects in stress tolerance, judgement, abstract reasoning persist; many function at reduced levels in society.

*Prepared by Professional Staff Association, Rancho Los Amigos Hospital, Inc. Downey, CA. Authors: Chris Hagen, Ph.D., Danese Malkmus, M.A., and Patricia Durham, M.S.

EXCERPTS FROM THIS ARTICLE ARE ATTACHED

Ethical & Policy Issues in Rehabilitation Medicine

by Arthur L. Caplan, Daniel Callahan and Janet Haas

A Hastings Center Report
Special Supplement/August 1987

This Special Supplement was derived from The Hastings Center project on Ethical Issues in Rehabilitation Medicine, which was supported by a grant from the Mabel Pew Myrin Trust. This Special Supplement was edited by Margaret Fletcher Stack. Contents copyright 1987 by The Hastings Center. All rights reserved.

The field of medical rehabilitation is relatively new, a product in great part of the rapid developments of medical science during and after the Second World War. Until recently, the ethical problems of this new field were neglected. There seemed to be more pressing concerns as rehabilitation medicine struggled to establish itself, sometimes in the face of considerable skepticism or hostility. There also seemed no pressing moral questions of the kind and intensity to be encountered, say, in high-technology acute care medicine or genetic engineering. With eyes focused on the dramatic and wrenching problems, those in biomedical ethics could and did easily overlook the quiet, less obtrusive issues of rehabilitation.

With the support of a grant from the Mabel Pew Myrin Trust, The Hastings Center set out in 1985 to rectify that situation. Various friends and colleagues in rehabilitation medicine had for some time been pointing out to us the wide array of moral issues confronting the field. They ranged from some familiar issues at the clinical level—informed consent, truth-telling, paternalism—to some no less familiar at the societal level, such as the allocation of scarce resources. Yet if these issues were, in one way, familiar, their context was different from acute care medicine, often strikingly so. Rehabilitation therapy is a long process, often allowing much time for the moral struggles to unfold and play themselves out. There is a great need for active patient participation in his or her own treatment as well. Use of treatment teams and the frequent need for family involvement add their own special ingredients to the medical and ethical mix.

To explore the issues, the Center assembled a group of practitioners in the field, Hastings Center staff members, and individuals experienced in other areas of medical ethics. For project participants, there was a difficult and extended period of exploration and analysis; the issues were surely there, but they were not always easy to define with precision or to pursue with vigor. Unlike other areas of medical ethics, there was little pre-existing literature, no specialists in the moral problems, and no tradition or history of interdisciplinary work between rehabilitation and ethics. It was, in many ways, one of the hardest projects ever

mounted by the Center, not simply because the moral problems encountered were complex, which they were, but because they often seemed elusive. We ended the project with a sense that we had made some progress, but humbled that we had made less progress than we would have liked. There is still much work to be done.

The report that follows was written by Arthur Caplan and Daniel Callahan, assisted by Dr. Janet Haas of the Moss Rehabilitation Hospital in Philadelphia. It owes much, however, to the project participants, who gave gladly of their time, research, and insights. A separate collection of papers and case studies developed by them is being prepared for publication. We acknowledge with gratitude their help. We no less want to acknowledge the support of the Mabel Pew Myrin Trust.

—Daniel Callahan
—Director

Hastings Center Report, August 1987

Until recently the ethical issues in the field of medical rehabilitation had received relatively little explicit attention. Most clinical practitioners or scholars in philosophy, theology, law and the social sciences focused their analyses of moral problems in health care almost exclusively on emergency or acute medical interventions.

In part, such neglect may be a result of the fact that rehabilitation is a relatively new specialty within the realm of health care. Rehabilitation only began as a distinct field during World War II when such pioneers as Howard A. Rusk and Henry Kessler, building on the work of Frank Krusen, demonstrated the efficacy of rehabilitation to return soldiers to active duty rather than mere convalescence. The medical specialty was created in 1947 with the formation of the American Board of Physical Medicine under the guidance of Frank Krusen. To date, fewer than three thousand physicians are certified as specialists in rehabilitation medicine.

However, the newness of the field is not an entirely satisfactory explanation for such analytical neglect. Other recently developed areas of health care such as neonatology have produced a great deal of ethical discussion. Obviously, there must be other factors that have caused ethicists and practitioners to overlook rehabilitation medicine.

Rehabilitative therapy depends upon the efforts of many different health care specialists, both physicians and non-physicians. Their efforts frequently extend over long periods of time. Moreover, rehabilitation rarely results in dramatic "cures." Normally, it does not make extensive use of life-saving technologies. Without the use of these dramatic interventions, the moral questions become more amorphous, less obviously responsive to established ethical paradigms.

Those most often in need of rehabilitative services are those already undervalued by the society. Many are elderly. Some have congenital disabilities. A large proportion are unable to work. In a society that places great value on youth, vigor, and industriousness, and manifests an ongoing trust in the power of science and medicine to reverse the effects of disease and disability, there are powerful stigmas and little prestige associated with patients who lack both highly valued characteristics and the capacity for cure.

In spite of these obstacles, in the past few years there has been a significant increase of interest within and outside the field of rehabilitation medicine in ethical issues. In part, this reflects changes in social attitudes toward disability. Some of the stigma associated with physical and mental impairment has begun to wane as a result of concerted efforts by consumer advocacy groups, rehabilitation professionals and self-help organizations such as the Independent Living Movement.

In part, the sudden spurt of interest in rehabilitation ethics is a response to increasing pressures to contain costs. Discussions about the desirability of introducing some form of prospective payment or capitation-based financing into rehabilitation have encouraged professionals in the field to examine seriously their moral obligations both to their patients and to society.

And, in part, because persons with severe neurological injuries can survive for increasingly longer periods of time, rehabilitation professionals must begin to address the moral dilemmas raised by treating patients whose capacity for independent living or autonomous behavior may be moderately or severely impaired. While small in overall numbers, the class of patients receiving rehabilitation who are brain injured are highly visible to providers, administrators and third party payers in terms of both costs and the level of resources they utilize.

It is clear, then, that medical rehabilitation differs in many important respects from emergency or acute medical care. It is also clear that interest in the unique ethical issues of rehabilitation is on the rise. It is, therefore, essential both for bioethicists and for those who deliver or receive rehabilitative services to identify the salient moral dilemmas and to determine whether ethical analysis based on emergency or acute care paradigms is adequate.

Decisions to Admit Patients to Rehabilitation

One of the most distinctive aspects of rehabilitation in the United States is that practitioners choose their patients. Disabled Americans are not, in general, entitled to reimbursement for rehabilitative care. Nevertheless, historically, the supply of such care has fallen short of the demand for it. Clinical practitioners faced with the reality of a demand that exceeds supply have had to review potential patients in order to select those who would receive treatment.

Generally speaking, decisions as to whether rehabilitation will be initiated involve a two stage process. Most of those who receive rehabilitative care are referred by physicians practicing in acute care settings. Once a referral is made, a decision must then be made as to whether a patient is an appropriate candidate for rehabilitation.

Some physicians do not consider rehabilitation as an option with the result that physiatrists are not always given the opportunity to consider the possibility of transferring a patient to a rehabilitative setting. The selection is difficult to challenge either by the patient or members of the rehabilitation team since no formal mechanisms exist for review of decisions at this stage of the rehabilitation process.

Once a referral has been made, it is usually a physiatrist who screens potential candidates for rehabilitation. The information used to make initiation of treatment decisions is derived from patient records, consultation with other physicians who have already treated the patient in acute or emergency settings, and usually, but not necessarily, direct physical examination of the candidate. Unfortunately, communication between physicians in acute and rehabilitation settings is not always as comprehensive as it ought to be.

When referrals are made, physiatrists consider a variety of medical and nonmedical factors in determining whether or not to initiate rehabilitation. In the area of nonmedical factors, potential candidates will have their financial and insurance status reviewed by administrative personnel. Social workers may review a potential candidate's family or social situation. The primary reason for such an assessment is to insure that the disposition of the patient will not be a problem once rehabilitation has been completed.

Among medical factors, diagnosis and prognosis are paramount considerations. Some physicians believe that persons with particular types of impairments, such as those resulting from stroke or spinal cord injuries, are likely to demonstrate functional gains from rehabilitation. Other diseases such as Alzheimer's or terminal stages of cancer are viewed by some as being less amenable to successful intervention and therefore of lower priority in access to treatment.

Relatively minor impairments in cognitive or sensory capacities may be given great weight since these deficits may significantly impair the patient's ability to participate in a rehabilitation program. Or the physician may believe that the degree of effort and amount of resources necessary to help patients cope with cognitive or sensory dysfunction may be so large as to diminish the availability of resources for other patients.

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Senator HARKIN. Thank you very much. The reason I had you go first, is that I was waiting for my esteemed colleague and good friend, Senator Cochran from Mississippi, to arrive to introduce our next witness.

Senator COCHRAN. Thank you very much, Mr. Chairman. I really appreciate your convening this hearing and trying to direct our committee's attention to some of the problems which we face in the area of trauma, head injuries, and rehabilitation services that are available, or are not available, to those who could really benefit from a more committed response from our Government, both the Federal and local levels.

Today, it is a pleasure for me to be able to present our State's finest physician in this area of head injury and neurological disease services, Dr. Howard Katz, who is at the Mississippi Methodist Rehabilitation Center in Jackson, Mississippi. He is from Memphis originally, but did a residency at Tufts University in Boston, and came to our State a few years ago and has provided a tremendous amount of leadership in this area.

I must say that we are on the road to becoming one of the leading areas for medical services in this very important health care area. We need to do more in the rehabilitation effort in our State, as many other States do, but I am glad that we have the chance to hear from him.

He has done a great deal of work on a paper, which he has presented in the form of testimony to our committee, and I urge everyone to take a look at it. There are some common sense suggestions that he includes here for action that can be taken to improve our response to this very important problem area.

Without taking more of his time, Mr. Chairman, I would like to introduce to the committee, Dr. Howard T. Katz of Jackson, Mississippi. We welcome you and appreciate your being here.

Dr. KATZ. Thank you very much, Senators, and thank you to the National Head Injury Foundation, to Marilyn, and to all the head-injured survivors and families that are here and that I represent from across the country, and in particular, the great State of Mississippi.

Head injury is a big problem. I hope that by the time I finish testifying today, you will know that head injury is a problem that you can do something about.

In my written testimony, which I cannot go over completely here today, I make numerous recommendations to help brain-injured people and their families. I wrote this only after consulting with survivors, family members, physicians, nurses, therapists, attorneys, and educators, a true interdisciplinary team, each devoted to preventing brain injury or improving life thereafter.

I do not have time to make all those recommendations today. In my written document, I divide what you can do into three categories: prevention, education, and funding.

In my presentation today, I will make one recommendation in each category.

First, prevention. Thousands of children under the age of three drown in private pools annually in the United States, and thousands more live, but suffer brain injury. Three separate large-scale studies have demonstrated that a four-foot high perimeter fence,

with self-locking gates, can reduce these accidents by as much as 99.9 percent.

Hundreds of thousands of brain injuries can be easily prevented at little or no cost to the Federal or State Government.

Second, education. Education is needed at all levels, education of families, survivors, ambulance and emergency room clinicians, medical doctors, allied health personnel, communities, law enforcement agencies—very important—vocational counselors, and educators is desperately needed, as is research in all of these areas.

Public Law 94–142 requires that a free appropriate education be provided for all children regardless of the nature or severity of their handicapping conditions. Yet, head-injured children are provided with an education, which is free, but inappropriate to their needs.

One reason is that diagnostic processes used to place children into educational categories do not adequately evaluate the learning and behavioral styles of the head injured.

To complicate matters, in the first few years after a head injury, a student is in a state of recovery, and his abilities and needs change constantly.

Typically, students with severe head injuries completely baffle school systems and the personnel, while those with mild injuries are mistaken for "normal" and deprived of needed services.

In the schools' defense, most of the problems result from lack of awareness in education, not from negligence or malice. Head-injured students need an educational funding category of their own. Counseling for these students is greatly needed, and so are educated counselors.

The behavior of a brain-injured student must be understood in proper context, and appropriate, not demeaning or humiliating, behavior modification programs need to be instituted. These require better trained personnel.

In my written testimony, I recommend many other ways education can improve the quality of life for head-injured survivors, their families, and communities at little or no cost to the Government.

Finally, funding. Funding issues are always a problem and funding from Government does need to be increased for programs and research, and I agree with the need for the catastrophic insurance that they are talking about today, but I would like to take a moment to explain how private insurance companies shift the cost of care to the Government. In my opinion, they rip off the consumer and the Government.

A clause contained in almost every private insurance policy states that once a patient is Medicare-eligible, he is no longer eligible for payment through his own insurance policy. He may think he bought a million dollars worth of coverage, but once Medicare starts paying, 30 months after the injury, the private insurance company simply stops no matter how little has actually been paid.

To further reduce the amount they have to dish out, insurance companies use another clause they term "medical necessity." This means that they hire a nurse several thousands miles away from your house and the hospital and the patient, of their own, to decide whether the hospitalization or piece of equipment is appropriate.

The nurse often takes three months, maybe six months, maybe nine months to even give you answer. Meanwhile, the months go by. Suddenly 30 months have passed, the patient is Medicare-eligible, and then it is the Government's problem.

Some insurers refuse to pay because the insured person has failed to fill out the proper forms for Medicare, and if they had filled out the proper forms, they would be Medicare-eligible. He may have been in a coma at the time that he was supposed to have filled out those forms, but that is his tough luck.

I am tired of this game, and so is the consumer. You can help change these practices.

Today, you have heard one recommendation in each of the three categories: prevention, education, and funding. There are many more in my written testimony, and I ask that you read and consider them. The take-home message today is that head injury is a big problem, a problem you can do something about.

Thank you.

[Applause.]

[The prepared statement of Dr. Katz follows:]

TESTIMONY TO THE

UNITED STATES SENATE SUBCOMMITTEE

ON THE HANDICAPPED

RECOMMENDING SOLUTIONS TO SOME OF

THE PROBLEMS ENCOUNTERED BY

HEAD INJURED SURVIVORS

AND THEIR FAMILIES

SUBMITTED BY

HOWARD T. KATZ, M.D.
CHIEF OF HEAD INJURY SERVICES

APRIL 12, 1988

86-558 0 - 88 - 4

Mississippi Methodist Hospital and Rehabilitation Center, Inc.
1350 E. Woodrow Wilson Dr. • Jackson, Mississippi 39216 • Phone (601) 981-2611

INTRODUCTION

BACKGROUND

Thank you very much for asking me to testify. My name is Howard T. Katz, M.D. I am originally from Memphis and graduated from medical school there before training in my specialty of Physical Medicine and Rehabilitation at Tufts New England Medical Center in Boston. After completing my residency I moved to Jackson, Mississippi, to be Chief of the Head Injury Service at the Mississippi Methodist Rehabilitation Center (MMRC). As a family member of a head injured survivor and as a professional dedicated to maximizing the quality of life of head injured people, I recognize the importance of my testimony today.

Head injury has been called the silent epidemic. Approximately 500,000 head injured patients require hospitalization annually in the United States and 74-98,000 of these live with moderate to severe disabilities. Over 66% of these people are under 35 with long life expectancies. Most are male. Recent estimates have placed the direct and indirect cost to society at 75-100 billion dollars a year to care for the head injured. This figure does not include loss of productivity and potential wages nor the impact on the social and human services system. Last year approximately 10,000 head injuries occurred in Mississippi - 8,000 minor, 1,000 moderate, and 1,000 severe.

PURPOSE

The purpose of this report is to suggest solutions to some of the problems and frustrations experienced by the survivors of head injury and their families.

HEAD INJURY IS A PROBLEM YOU CAN DO SOMETHING ABOUT!

What can be done can be divided into three areas: prevention, education and funding.

PREVENTION

Trauma to the head is a major social and health problem in the United States. More Americans between the ages of 1 and 44 die as a result of trauma than from any other cause. Each day in the United States, 1,500 head injuries occur, 275 of them fatal.

Such injuries can be prevented with three basic strategies at little or no cost to the federal government.

1. Persuade persons at risk of injury to alter their behavior for increased self-protection by education; i.e., use seatbelts and practice water safety.
2. Require behavior change by law or administrative rule; i.e., laws requiring the use of seatbelts and the installation of perimeter fencing of swimming pools.

3. Provide automatic protection by product and environmental design; i.e., installation of seatbelts that automatically encompass occupants and flotation devices that protect children from drowning.

Although each of these strategies has a role in head injury prevention, laws are more effective than education, and product and environmental design more effective than laws.

The three main sources of head injury are transportation accidents, falls, and sports and recreation accidents.

TRANSPORTATION ACCIDENTS

Almost half of all head injuries are caused by motor vehicle accidents. Of the head injuries treated at MMRC in the past year, three-fourths were caused by motor vehicle accidents.

To prevent these accident-related problems, we should:

1. REQUIRE THE USE OF EFFECTIVE, AVAILABLE TECHNOLOGY IN THE MANUFACTURE OF CRASHWORTHY MOTOR VEHICLES (e.g., air bags, crashworthy seats, side impact and rollover protection).
2. REQUIRE STATES TO PASS SEATBELT LAWS IN ALL STATES IN ORDER TO QUALIFY FOR FEDERAL HIGHWAY MONIES.

3. REQUIRE FEDERAL CRASH TESTING OF SEATBELTS AND AIR BAGS (at 65 mph).
4. PROMOTE SAFE TRANSPORTATION (e.g., interstate reporting of drunk driving).
5. PROMOTE THE MANUFACTURE OF SAFER MOTORCYCLES (e.g., crashbars, anti-lock brakes, improved visibility).
6. ENACT HELMET USE LAWS (for riders of motorcycles, mopeds, bikes and skateboards).
7. RECALL ALL TERRAIN VEHICLES (New ATVs must be required to incorporate stability, safe handling, adequate suspension, crashworthiness, and maximum speed of 20 mph).
8. ENCOURAGE THE PORTRAYAL OF SAFE BEHAVIOR IN THE MEDIA (children in child restraints, the use of seatbelts, the use of helmets).
9. IMPROVE THE CRASHWORTHINESS OF HEAVY TRUCKS (better anti-lock brake systems, side and rear underride guards, and interior automatic crash protection.
10. IMPROVE THE DESIGN AND SAFETY OF HIGHWAYS (break-a-way signs and utility poles, impact attenuators at exits, roadway barriers to separate oncoming fast-moving traffic).

FALLS

More than 14,000 persons die of injuries from falls each year. Falls are the second leading cause of head injury, especially in the high-risk groups of young children and elderly adults. Preventive measures for children include energy-attenuating surfaces under high structures and swings at playgrounds. For elders, the floors of long-term care facilities also should have energy attentuating surfaces. For all persons, windows above the first floor should have "fall proof" physical barriers; there should be adequate lighting and railings on stairs in public buildings; and walking surfaces in high-risk areas should have adequate friction.

SPORTS AND RECREATION ACCIDENTS

Ten percent of all brain injuries results from sports and recreation injuries, especially from football, baseball, and basketball. Boxing and ice hockey also present frequent head injuries.

Drownings account for 6,000 fatalities per year in the United States; they are second only to motor vehicle accidents as the cause of death in the adolescent age group.

Cerebral anoxia by near drowning is a frequent brain injury. Yet, evidence suggests that four-foot high fences and self-locking gates around pools can reduce drownings by as much as 99.9%. Mandatory cardiopulmonary resuscitation training for pool owners is also recommended.

EDUCATION AND RESEARCH ON PREVENTION OF HEAD INJURIES

Currently, there is no single coordinated focus of activity to call attention to head injury or to permit an organized program to attack this problem. Just as there is a Center for Communicable Disease Control in Atlanta, Georgia, under the Department of Health and Human Services, there needs to be a Center for Injury Control within the federal government. This center would institute a national injury program in the following manner:

1. Support research in biomechanics, injury epidemiology and prevention, acute care, and rehabilitation.
2. Establish injury surveillance systems and conduct injury prevention projects.
3. Improve and expand professional education and training.
4. Establish centers of excellence in injury biomechanics, prevention and care.
5. Collect and analyze data on injury.

6. Serve as clearinghouse and lead agency among federal agencies and private organizations interested in injury research and prevention.

Traumatic injuries, including head injuries, are the largest cause of death and disability of children and young adults in the United States. Prevention of these injuries, possibly through a Center for Injury Control, must be the focus of research in the late 20th century just as communicable disease control was the focus of research in the early 20th century.

EDUCATION

From the moment of injury through final reintegration of the patient into the community, education is imperative. Better education will help the patient, the family, the health service professionals, and the whole community. This section of my report stresses the need for education at every point in the patient's road to recovery.

AMBULANCE AND EMERGENCY ROOM CARE

Most of the damage to the brain in trauma does not occur as a direct result of the physical blow to the head. Rather, it results from unregulated blood flow and swelling. Therefore, the earlier the appropriate intervention, the better the person's chances to avoid serious disability. Treatment should begin at the site of the injury.

These recommendations will enable us to treat trauma

patients more speedily and appropriately:

1. 911 emergency numbers should be available.
2. More neurosurgeons are needed.
3. Air ambulances should be more widely used.
4. Emergency personnel should be better trained to detect covert brain injury.
5. Neurosurgeons should be better trained to recognize minor head trauma.
6. Family support should begin in the emergency room. This should be done in cooperation with the national and state head injury alliances.

INTENSIVE/ACUTE PHASE OF HEAD INJURIES

The event creating a head injury usually occurs without warning. The family is suddenly in a profound state of shock, not knowing what to do except wait. Meanwhile, many head injured patients move rapidly through hospital systems. The severely injured usually end up in an intensive care unit of an acute care hospital.

During the first quarter of the century, 60-70% of all head injured patients died. Today, modern medicine and technology allow many more patients to survive. Crucial to the survival of the head injured patient in intensive care units are stabilization and prevention of medical complications.

The education of all those involved in caring for the patient in the acute setting is important. This must include everyone from the doctors to the family members. Another crucial issue is the early initiation of rehabilitation. Rehabilitation cannot be deferred until the patient is transferred to a rehabilitation facility. Ideally, rehabilitation should begin in the Intensive Care Unit, even for patients in a coma.

During the intensive/acute phase, families of head injured patients in the Intensive Care Unit suffer through a period of intense grief, shock, guilt, and confusion. Many times they do not know if their loved one will live or die. These families' immediate needs are medical information, counseling, and the emotional support of a person who has traveled the same road.

The two most significant problems associated with the ICU/acute phase of a head injury are:

1. Inadequate awareness of the need for early rehabilitation.

   Solution:

   a. Better education of the staff in acute care institutions nationwide.

   b. More research to document the effects of early rehabilitation in the Intensive Care Units.

2. Lack of public familiarity with the National Head Injury Foundation.

   Solution:

   a. More funds for the NHIF to use in educating both the public and the health industry about the Foundation and head injuries.

   b. Information about NHIF with national and local contacts placed in all Emergency/ICU waiting rooms.

FAMILY

The most consistent and stable area of a head injured patient's long road to recovery is the family. Yet family members must handle situations for which they have had little or no training. From the moment they hear of the patient's injury, family members suffer tremendous stress. Aside from the crisis of the patient's sudden injury and tortuous road to recovery, the family must deal with money worries, insurance problems, and their own feelings of anger, guilt, and hopelessness.

For these reasons, both the patient and family need treatment. Among the types of treatment available are group therapy, individual psychological counseling, and social work intervention.

11

To coordinate the treatment of both the patient and the family, a case manager is needed. This person follows the patient through his term of care, offering recommendations for cost-effective strategies. He deals with medical, legal, educational, and vocational matters, and is aware of all available resources. The case manager's job includes (1) assessment, (2) coordination and referral, (3) treatment, (4) monitoring. Currently, this role is sometimes played by the vocational rehabilitation counselor; but in more than 50% of cases, there is no case manager. For every head injured patient and his family, a case manager is needed.

PHYSICAL MANAGEMENT DURING ACUTE REHABILITATION PHASE

In rehabilitating a head-injured person we strive to return an individual to pre-injury status as much as possible, and as quickly as possible. To do this, a special setting -- a rehabilitation center -- is needed with specially trained individuals.

Reasons for rehabilitation are:

1. To optimize long-term function. The sooner treatment is initiated, the better the outcome. Most physical recovery takes place over the first 18 months after injury, with the greatest amount

during the first six months. The rehabilitation team tries to: a) restore old skills, b) teach new skills, c) retrieve lost ground, and d) influence attitudes of the patient's family and the community. The family needs to be prepared for the kinds of difficulties likely to occur, and to be given realistic short-term objectives and some hint of the ultimate degree of recovery that is expected.

2. To retrain the brain. New pathways are learned to transfer information. Recent studies show that damaged brain tissue can regenerate.

The acute rehabilitation program requires a team of professionals working together. The physiatrist usually leads the rehabilitation team in designing individualized treatment programs and in prescribing proper medication, injections and surgery. Other members of the rehabilitation team include: nursing personnel, speech pathologists, occupational therapists, physical therapists, social workers, respiratory therapists, psychologists, orthotists, and recreational therapists. Additional physicians and allied health personnel are consulted as necessary.

Some of the common physical problems addressed are: respiratory dysfunction, disorders of eating and swallowing, communication problems, loss of mobility, dependence in self-care, and sexual dysfunction.

COGNITIVE PROBLEMS

Along with physical problems, head injury bring with it a number of cognitive and emotional difficulties. These include shortened attention span, reduction of visual and perceptual fields, and loss of impulse control and other developed skills. These difficulties may impose even heavier burdens on families than the physical handicaps. Marriage problems, difficulty with household management, loss of friends, and loss of employment can result from even minor head injury.

Cognitive rehabilitation involves a dynamic team approach. At MMRC, the cognitive rehabilitation team includes, among others, family members, a physiatrist, neuropsychologist, speech pathologist, occupational therapist, nurses and social workers.

Evaluation of cognitive deficits is a complex, ongoing process necessary to prescribe appropriate intervention. Rehabilitation may include intensive inpatient hospital care and/or outpatient care. The goal of therapy is to strengthen functional skills, gradually preparing the head injured persons for reentry into society.

The following case study illustrates the cognitive difficulties and cognitive rehabilitation of a brain injured person. Levi, a 35 year old black male, experienced a brain injury in October, 1985, as a result of being hit on the head by a falling ladder. He began to experience difficulties in performing job tasks that prior to the injury were routine. These problems forced him to give up two jobs at a local college. Reduced performance also threatened his third job, as a salesman of electronic equipment.

He was initially seen at MMRC on February 3, 1987. Cognitive therapy was recommended but not initiated, for Workman's Compensation denied payment for such therapy.

On October 10, 1987, he was evaluated for speech/language problems and admitted to therapy despite continued lack of funding. By this time his communication problems had affected his competence, competitiveness and confidence.

Cognitive therapy was initiated and by Christmas, two months later, he had won two awards for increased sales.

BEHAVIOR DISORDERS

"Sometimes I cursed, sometimes I hit and kicked. I wasn't OK. I couldn't move like I did yesterday ... no it wasn't yesterday and it never will be tomorrow - never!" (14 year old head injured person)

Behavioral disorders make the patient difficult for nurses, therapists, and physicians to treat, for the family to accept and for communities to handle. Two basic types of behavior disturbances encountered in head injury are disorders of control and disorders of drive. Typical behavioral problems are assault, impulsivity in action and verbal expression, inappropriate "vile" humor, disinhibition, rage, severe mood swings, and inappropriate sexual verbalization and action. An individual may manifest all or some of the behavior disturbances.

Behavioral management programs are used to treat these disorders. Among the options are a token economy or other reward system, time out, coping time, and isolation from activity.

In developing behavior management programs the following are necessary: (1) educated and adequate staff, 2) educated and supportive family, friends, and community, 3) a consistent and constant approach, 4) a protected, safe individualized environment, 5) clearly defined target behaviors and/or effective documentation.

Obstacles to completing and maintaining adequate behavior programs include:

1. Lack of educators.
2. Lack of funding for education and programs.
3. Lack of documentation.
4. Lack of follow up research.

5. Lack of a safe and protected environment to allow expansion of individual development.

RECOMMENDATION FOR IMPROVED PHYSICAL, COGNITIVE, AND BEHAVIORAL REHABILITATION OF BRAIN INJURED PERSONS INCLUDE:

1. Remove environmental barriers in the community (inaccessible facilities).
2. Educate the public to the physical, cognitive, and behavioral abnormalities associated with head injury.
3. Make public transportation more conducive to the handicapped.
4. Educate law enforcement agencies to the special needs of the head injured.
5. Improve existing centers by:
   a. Encouraging the continuing education of staff.
   b. Encouraging professional schools to include training about head injury.
6. Develop a national data base of information on head injured persons. This will help assess preventive and therapeutic techniques and improve them.

7. Make a professional educator part of the rehabilitation team, for education is an important aspect of all programs for patient, family and community.

COMMUNITY REENTRY

Recent strides in medicine have created an entirely new population of brain injury survivors who 10-15 years ago would have died.

Rehabilitation now extends past acute care in a hospital, past acute rehabilitation, and to the point that we must provide long-term community living services.

Community reentry for the head injured is a process, a philosophy, an attitude that we must develop if this new population of survivors are to reach their potential. When community-appropriate services are not available, the very basic values of human worth, dignity and respect are at risk.

One function a community performs is maintenance and enhancement of a way of life. Another function is the satisfaction of common needs, interests and ambitions. In the case of the head injured, few resources are available for a group particularly vulnerable to discrimination. Further, many head injured persons appear to be within normal limits of physical and intellectual functioning because obvious disfigurement is lacking. Yet in reality, memory skills, good judgement, and

socially appropriate behaviors are impaired. Skills are lacking which are necessary to process and provide order to the environment and as a result, interactions with the community are difficult.

Several options for reentering the community are possible:

1. Home Care

   After medical treatment, most head injured persons return to their families. Yet problems exist in the provision of respite care, day care, appropriate equipment, counseling and personal care attendants.

2. Transitional Living

   While complete independence is not always possible, transitional apartments and group homes often provide optimal independence.

   Needs include funding, supervision, personal care attendants, transportation, equipment, public education and vocational opportunities.

3. Long-Term Care Facilities

   Many of the more severely disabled may not be able to return home, and will require 24-hour care and supervision and not just warehousing in a nursing home.

   Needs include funding, facilities and appropriate therapy and nursing care.

Obstacles to community reentry of head injured persons include:

1. Lack of socialization opportunities.
2. Lack of vocational training programs and job placement specifically addressing head injury.
3. Lack of educational programs specifically designed for the head injured.
4. Lack of counseling for families and survivors.
5. Need for case managers.
6. Inaccessibility of programs to the under- and uninsured.
7. Lack of trained attendants and appropriate funding.
8. Dearth of education and public awareness of brain injured persons' special needs.

TRAUMATIC BRAIN INJURY - EDUCATION ISSUES

The enactment of Public Law 94-142 in 1975 required that a free, appropriate education be provided for all children regardless of the nature or severity of their handicapping condition. The legislative action was preceded by the school desegregation decision Brown vs. the Board of Education by more than 20 years, thus making the educational rights of handicapped individuals one of the final battlegrounds. Head injured children and adolescents are currently provided with free education but these services are frequently inappropriate to their unique needs.

Public Law 94-142 lists head injury among the handicapping conditions under learning disability. However, head injured children have cognitive, communication, physical, social and behavioral characteristics that are typically quite different from those of learning disabled children. Special education teachers, as well as most other school personnel, do not receive training about the nature of head injury; therefore, they rarely distinguish head injured children's needs. Unfortunately, due to inadequate testing procedures, some head injured students may be labeled "mentally retarded." Others, upon displaying behavioral disturbances present to some degree in most head injured children, are placed in classrooms for emotionally disturbed children. Again, these classifications ignore individual needs of the head injured and may exacerbate their problems. It is important to remember that even severely head injured people have memories of themselves as "normal" prior to their injury, and it is easy to see the negative effects to self-esteem caused by placement in a class for retarded individuals.

Diagnostic processes used to place children in educational categories may be adequate for assessing other handicapped populations, but are not designed to evaluate the learning and behavior style of the head injured. In addition to physical differences and perceptual deficits (e.g., visual and hearing

problems), head injured students during the first years after injury are in a state of recovery and their abilities and needs change constantly. Also, most school psychologists are not trained in assessing head injured students and are really not aware of adaptations and modifications needed to achieve accurate results.

With referral to any special education category, a problem arises from the sheer volume of required paperwork, which may take weeks or months to complete. In the interim, the head injured student is often in "limbo" and may lose the skills regained in the rehabilitation setting or develop inappropriate behaviors, due to lack of a structured environment.

Typically, students with severe head injuries completely baffle school personnel as to what to do while students with mild injuries are mistaken for "normal" and are deprived of services. In the school's defense, most of the problems result from a lack of awareness and education, rather than negligence.

A typical case history is that of Joey, a 16 year old male who sustained a gunshot wound to the head on September 21, 1986. He was admitted to MMRC on October 27, 1986, for intensive rehabilitation. He was discharged home on June 5, 1987. At the time of the initial speech/language/cognitive evaluation, Joey displayed severe impairment in all areas. Joey's verbal output was extremely low; his highest response level was one word at a time. He followed simple three-step directions but not complex

commands. He had such cognitive problems as severely decreased attention span, agitation, distractibility, and repetition of previous response. Reading and spelling skills were at the simple word level. Behaviorally, he often refused to attempt tasks and left the therapy room; also he often made strange faces, flailed his arms, talked to himself, stared and touched people inappropriately. When Joey was in unstructured situations, his distractibility and confusion increased considerably. Upon discharge from MMRC, Joey's academic skills were at primer levels. Speech and language skills remained severely impaired. Behavioral differences were still evident.

Joey's school system was contacted during the final months of his stay at MMRC and they were invited to meet with MMRC staff to plan Joey's school reentry. This invitation was not pursued. Information about head injury, a neuropsychological evaluation, and in-depth reports and recommendations were sent to the school from MMRC. Yet the school apparently did not use this information. Joey was placed in learning disabled classes - English, math, biology - that were far too advanced for him. He began to display severe behavior disturbances in response to his frustration. The school did not contact MMRC directly but sent a letter by one of Joey's teachers with Joey when he came to MMRC for a checkup. The letter reflected the teacher's complete lack of understanding of head injury and its consequences. She asked what type of punishment to use with Joey, not realizing that his

behaviors were at least partly in response to inappropriate placement and teaching strategies.

A speech pathologist from MMRC traveled to the school to determine with the school staff more beneficial management of Joey. It was decided against our advice that Joey would receive one hour of speech therapy each day and one hour of home bound services each afternoon (individual teaching in Joey's home). It was recommended that Joey attend school for socialization purposes only for one hour daily - an appropriate academic class was not available. The special education personnel then stated that school attendance for socialization purposes only could not be permitted according to the State Department of Education guidelines.

Recommendations for returning head injured students to the classroom are as follows:

1. Head injured students need an educational funding category that specifically addresses their needs.
2. Teachers and administrators in schools need adequate training for assessing and planning remediation programs for the brain injured. The problem could be remedied by a team approach, including case manager, speech pathologist, classroom teacher, school counselor and an administrator who would deal with discipline and scheduling problems.

3. One of the greatest needs is counseling. This could be arranged through local Rehab Centers - schools could contract for services if they do not have a qualified counselor on the school staff. Or, special inservices could be provided for the school counselor.

4. Behavior of a brain injured student must be understood in proper context. Enforcement of rules must take into consideration his deficits such as impulsiveness and decreased judgement. A brain injured student must be treated fairly and with respect as an individual. This problem brings us back to education of the faculty and staff -- education about the student's rights and about the responsibilities of school personnel in providing these rights.

   Schools need provisions for alternative methods of discipline. Because of memory problems, need for repetition, etc., it is not appropriate to remove a brain injured student from classes and send him home for days. Because of his injury, he already falls behind and the burden of keeping up daily is enough without the gap of time. If discipline is necessary, then the school should provide appropriate in-school supervision. He should not be punished socially by being humiliated in front of peers. Suspension area must be removed from classroom and student areas.

Also, he must not be punished over and over because of previous incidents. Each problem must be dealt with immediately and fairly, then forgotten.

Along with punishment for inappropriate behaviors, the administration/teachers must provide the student with an appropriate alternative behavior. They can do that only if they have some understanding of his individual problems. Every team member needs to be made aware of infractions of rules and suggested alternative behavior so they can help the brain injured student to follow through.

5. Attention needs to be directed toward educating the brain injured student's peers before his return to school. Students at school expect the brain injured student to return and pick up where he left off -- or they simply do not know what to expect. So they are "afraid" of him or afraid of not knowing how to relate to him--and the end result is that the returning student is just left out.

If the teachers understand better, they can be role models for the students. Again, education of teachers is paramount.

I suggest that one group (such as a small service club or National Honor Society) be selected and provided with general information and be "trained" in how to

relate to the brain injured student. If at least a small group of students can be educated, the returning student will find acceptance and respect with some peers. Parents of head injured students can be involved in this effort as well.

The following letter from a parent of 16 year old head injured student illustrates the problems brain injured children face in our school system today.

TO ALL CONCERNED:

In the follow-up statements you will hear my views on the lack of knowledge and as bad as I hate to say it the lack of concern for the head injured student reentering the school system. My son is a graduate of the Mississippi Methodist Rehabilitation Center where he was a patient for 4 months after a car accident that left him in a coma for 3 1/2 weeks. We informed the school system that he would need support from them.

They did place my son in a regular classroom setting with extra resource classes and he does well in these setting. However, Dr. Katz and his staff tried to make them aware that head injuries need to be dealt with accordingly which they've ignored because they are not interested enough to know what to expect nor how to handle it. A great majority of head injury students look perfectly normal, but their brain has been shaken and they sometimes get an overload and react differently to a situation that they wouldn't have before their injury. Right after my son's accident he got upset in the cafeteria because he was told he could only have 1 tiny cup of cheese and he had already had 2 on the tray and was walking off when the worker called him back and said that he could have only 1 cup. So he told her "She could have the damn cheese." Because of his spontaneous remark the Principal gave him 8

days of in School Suspension in a class with other kids in it.

However my son was made to sit behind a screen, was not allowed to talk to anyone, could not go to the lunch room, and was walked to the bathroom by a teacher. I find this very demeaning. He had many problems in the beginning just trying to adjust to the injury, not being able to drive, play sports, and be with his former friends as he had to repeat year. But he made it through. But another episode came up and he went back went back behind the "iron curtain," this time for 10 days.

It's a shame that the individual that doles out his punishment has not tried to find the reason and the why's of how the head injured person reacts to these situations. I personally feel that he does not care. As I write this letter my son has just been handed another 10 days' confinement. This Principal has totally ignored the medical advice concerning my son. All he's concerned with is having a perfect school with perfect kids and to heck with those that have special needs and problems. He wants them hid away and out of sight, but these kids have every right to a normal classroom setting if they so warrant and special help if need be. I personally feel that every teacher, principal or anyone who has to deal with head injury students be made to have training. It could be reading and watching videos which are available to them and if not, it can be made available. The bottom line is there will always be head injuries and the Educational System must be aware and informed so these students can get what they need and deserve to be functioning adults. They do not need to be treated like they're animals or a prisoner.

VOCATIONAL REHABILITATION

Vocational Rehabilitation is a process by which impaired persons are trained for the work world. Some may go back to

their old vocations, but many must enter new, more appropriate jobs.

Job training and placement for head injured individuals is a complicated and difficult process. The public tends to be pessimistic about the rehabilitation and employment potential of the brain injured. Lack of understanding of head injury on the part of many vocational counselors adds to the difficulties.

Problems associated with Vocational Rehabilitation of the brain injured include:

1. Lack of acceptance of head injured clients by Vocational Rehabilitation counselors.
2. Lack of assistance with job placement.
3. Lack of education on head injury in the community, leading to decreased willingness of employers to hire the head injured.
4. Lack of knowledge about the best vocational rehabilitation techniques for the brain injured.

Solutions to these problems include:

1. Increased <u>funding</u> for Vocational Rehabilitation programs for the head injured.
2. More <u>legislation</u> to create the incentive to hire the handicapped.

3. During the acute rehabilitation phase, the entire rehabilitation team needs to work together to determine which jobs the patient is capable of performing. Appropriate professionals can educate employers of the individual's deficits and capabilities. Case managers can arrange these meetings.

4. The supported work model: This involves the use of an aide or coach to help the brain injured person on the job. The support person may be used temporarily to help the worker learn or relearn his job. In other cases the support person may be used permanently. The employer plays a role not only by allowing the presence of the job coach but by altering job responsibilities as necessary.

5. Model Programs: I would like to see at least three model state programs developed and implemented in 1988-89. An independent researcher, perhaps from a 4th state, should evaluate the efficacy and cost effectiveness of each and work towards establishing a national program. Some work in this area has been accomplished, and for this I thank you. Unfortunately none of this has been in the southeastern United States.

FUNDING

The severe injuries described and the consequences to the individuals may differ, but one thread runs consistently through this maze. All victims require funding for recovery, and limited funding dictates limited recovery.

Most people with medical problems rely upon insurance for payment of their medical bills. Although insurance companies advertise personal concern for the individual policyholder, their position is all too soon at odds with the patient, his family and health care providers. Initial notification to the company of a severe head trauma often starts the construction of a barrier that is not easily overcome. Head trauma means large claims. The experience of insurance claim clerks at MMRC indicates the emphasis is on finding reasons for refusal of claims rather than ways to return the victim to his previous life style.

Greg's case is a good example of this dilemma.

Greg was involved in an automobile accident on January 27, 1986. When he arrived in Jackson, Mississippi, it was noted that his brain tissues were protruding through his skull. He was comatose for 2 1/2 months. On March 3, 1986, the initial claim was made under his group's major medical insurance policy. The policy had a $1,000,000 umbrella coverage. The insurance company learned that the young man was quadriplegic. It implemented a new billing system to more easily monitor the number of

people involved in the group, whether premiums had been paid, etc.

On June 27, 1986, notice was given that the premium was being doubled. Anticipating cancellation because of the increased premium, the company then notified the local agent they were offering a conversion policy. This offer was made on July 10, 1986. The advice of an attorney was sought and the conversion was refused. It would have paid a maximum of $4,050.00.

On August 1, 1986, the premium was doubled. The young man's father again sought the advice of counsel and paid the doubled premiums until he could no longer afford to do so. He then resumed paying single premiums for six months.

By this point the other members of the group had been driven to a different insurance company by the doubled premium. The original company advised that because there were insufficient members to constitute a group, the policy would no longer be effective. At the time of termination, the young man's total medical bills amounted to $300,000.00. Although his insurance had been terminated, his needs were the same and he eventually filed a lawsuit in an effort to survive. The case has been heard, but no decision has been rendered and it may be years before a final decision is reached.

During this time the young man will be quite limited in the rehabilitation process and any other progress he might make

because funds are simply not available to provide for his needs.

If a company finds itself in a position where it must pay, efforts then appear to be directed toward limitation of payments. This may be done in the guise of increasingly popular "medical review" where registered nurses in some distant city and state review a patient's medical records and decide that certain services are not medically necessary.

Often, I have written multiple letters with lengthy explanations as to the medical necessity of a particular procedure, service, or piece of equipment. Weeks later, I have received a letter of denial with no explanation except that the insurance company finds that there is no medical necessity.

Too often, the companies initially award coverage and later deny it. This is what happened to Cynthia, a 16 year old woman who sustained a head injury on October 22, 1985, when she was struck by a car while getting out of a school bus. She came to MMRC from an acute care facility where she had been in intensive care for three weeks during which she required ventilator support. She had severe injuries beyond the head trauma and had developed complications prior to the time she was transferred to MMRC.

She had group insurance through a nationally recognized company and the party responsible for her injury had liability coverage. Both companies had contact with MMRC prior to her admission. The group insurance company advised it would pay for

two weeks' hospitalization. The liability carrier agreed to pay for six weeks, at which time her progress would be reviewed and extended coverage discussed.

She was discharged April 9, 1986. Several months later the Business Office at MMRC was advised by the liability carrier that the policy limits had been met and it would make no further payments on the hospitalization. Cynthia's family had to hire an attorney to obtain payment from the liability carrier's reinsurer.

One of the major problems in funding for the head injured patient is that companies exclude rehabilitation from coverage. The obvious reason is the cost involved. The average daily cost at MMRC for a head injury victim is $725.00 per day. If he requires respiratory care, the cost increases to $870.00 a day. A review of records at MMRC reveals at least 30 insurance company refusals of rehabilitation service since May, 1987.

So what happens to these people? Medicare is available, but the victim must wait a minimum of 30 months before he or she is eligible. During the waiting period the physical problems associated with head injury become complicated. Joint contractures develop. Swallowing disorders go unrecognized; if untreated they can lead to aspiration and pneumonia. At a time when the person should be recovering, he is actually

deteriorating. Antisocial behavioral patterns develop which, left untreated, become difficult to correct.

Oscar was the victim of delay in treatment. He developed a brain abscess of the right frontal parietal area in February, 1985. He remained in intensive care at University Medical Center, Jackson, Mississippi, for over five months. He had no insurance and was discharged.

When his Medicare became effective 30 months later, he was admitted to MMRC with a sacral ulcer. He had developed contractures resulting in decreased range of motion in both shoulders, both hips, knees and ankles and making it impossible to bring him to a standing position. Spasticity was evident, especially in his lower extremities. His sitting balance was poor and he was unable to sit up independently. The wheelchair he had did not meet his needs. Because of cognitive problems and poor vision, Oscar needed assistance with all self-care activities.

With all these difficulties his first admission to MMRC was limited by Medicare to 60 days. The emphasis during this time was on cleaning up the pressure sore, stretching the contractures, attempting to reduce spasticity and improving sitting balance transfers. An appropriate wheelchair was provided.

At the time of discharge he was improved to the point he required minimal assistance with lower extremity dressing and was

independent in upper extremity dressing. He could walk with maximal assistance and a walker. When he was next eligible for treatment under Medicare rules, he progressed further. He is now considered an excellent candidate for vocational rehabilitation. There is no doubt his recovery time would have been reduced and his recovery would have been more complete had he been able to obtain treatment when he was first released from intensive care. One can only speculate about the private hell he lived in while waiting for 30 months to expire.

A problem encountered daily is delay in payment for various reasons. It is common to be advised a company requires several weeks to decide whether to pay a claim. This delay frequently occurs because no one seems to know who is supposed to make the final decision. Concern for the patient is in short supply.

Too often the consumer does not understand the limits on the coverage he purchases. What seems to be generous at the time of purchase quickly dwindles in the face of serious injury. The disability policy which seems at the time of purchase to offer security is reduced by the amount of Social Security Benefits received. There is never enough money.

Most health insurers fail to recognize head injury as a specific diagnosis, separate from other medical groupings. This flaw in the system generates obstacles to reimbursement. This problem must be corrected.

Some recent reforms have proved helpful. Until the evolution of COBRA, persons with head injuries had no options available to them once a group insurance policy expired. Once an employer terminated an employee, his or her insurance coverage normally expired in 30 days.

With the inception of COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985) an individual now has access to an additional 18 months of coverage. The fact still remains, though, that upon exhaustion of the additional 18 months under COBRA, adequate/comprehensive insurance is not available. If it is available, it normally is very costly and excludes preexisting conditions!

The need for rehabilitation must also be recognized. Aggregate policy limits of health insurance may be so low that long-term rehabilitation efforts are thwarted. The policies also contain inside limits on number of hospital days, on skilled nursing facility days or on specific treatments. While the policies are sometimes acceptable for acute care rehabilitation, they give little consideration to the chronic care needs of persons with head injuries.

Policies should not be restricted to a particular type of rehabilitation such as physical therapy or speech therapy. Occupational therapy, recreational therapy and neuropsychology are also needed. Maintenance care is needed in the home for those unable to care for themselves.

An item lacking in many policies is provision of a case manager. This is a process which has cost containment as one objective, but its primary focus is organization and sequence of services and resources to respond to an individual's health care problem. A well-orchestrated case management approach insures that health care dollars are prudently spent. Over the long run, patient dependence on the health care delivery system is minimized.

Additional coverage is needed in the form of catastrophic riders. Catastrophic injuries are a small percentage of incidence of medically related claims. The rider would be added to an existing group policy at an additional premium, but would be well worth the cost.

Other insurance problems plague head injury survivors. Almost every non-group policy that is sold today contains a Medicare eligibility clause. What this specifically means is "that once a person becomes eligible for Medicare during any period such person either has coverage under Medicare, or, while otherwise qualifying for coverage under Medicare, does not have such coverage solely because such person has refused, discontinued, or failed to make any necessary application for Medicare coverage," no longer is he eligible for coverage under their commercial insurance policy. In most instances the policy cancels immediately.

I have heard of instances where non-group policies have been sold to families of head injured persons when, for all intents and purposes, they were null and void as the patient was already Medicare eligible.

One problem is that Medicare coverage is limited both in days and dollars allowed and does not really recognize catastrophic coverage. Secondly, due to the limited funding available under the Medicare plans, many providers are not willing to accept, treat, or care for Medicare patients.

Another problem with conversion from a group policy to a nongroup/individual policy is the significant reduction and limitation of benefits available to the insured. As in Greg's case cited above, when an insurance company can pass bills and premium increases on to an employer for an injured employee that is one thing. But when (under a nongroup policy) an insured is the direct liability of the insurance company, they want to cut their losses! In certain instances group policies recognize skilled nursing facilities as hospitals because of cost effectiveness. Yet once the patient converts to a nongroup policy (and the liability is the insuror's), the determination is that the facility is no longer recognized as a hospital and is thus subject to limited benefits.

Brochures that are given to employees/subscribers are generally brief and generic and do not clearly define benefits and policy limitations. Insureds often are not given access to their actual policy/contract which specifically defines available coverage with its limitations and special caveats, such as "medically necessary services."

How often do we see an insurance brochure that documents $1 million of coverage, or unlimited benefits for hospitalization, etc. What is written in every policy and not found in marketing brochure is the "medically necessary services" clause.

The bottom line is that the insurance company determines which services are medically necessary and which are not. They use delay tactics to minimize costs until the Medicare eligibility clause kicks in. The authority of the attending physician and treating staff means little.

Recommendations:

1. Insurance should pay for all rehabilitative services medically necessary.
2. A case manager should be provided for all head injured persons.
3. No health insurance should be cancellable by the insuror until the patient reaches maximum medical improvement or has spent the advertised limit of the policy.

4. "Medically necessary" should be defined as treatment and/or diagnostics deemed necessary by the attending physician and his patient. If the insurance company disagrees, the opinion of an independent head injury specialist must be sought.
5. If the insurance company is found to have been acting in bad faith, a large punitive damage judgement should be used to help finance some of the many needs of head injured persons discussed in this report.

CONCLUSION

I hope my testimony has revealed that the problems of the head injured in the United States can be drastically reduced. Prevention of injuries can save billions of dollars and prevent human grief and sorrow. To improve quality of life for head injured survivors and their families, we need to educate professionals and communities. Adequate funding is needed for rehabilitation. Finally, by assuring that $1 million worth of insurance actually pays for up to $1 million worth diagnosis and treatment, we can prevent insurance companies from transferring costs to the government and provide a true sense of security one is supposed to feel when he purchases adequate insurance coverage.

Thank you for your time and interest.

Respectfully submitted,

Howard T. Katz MD

Howard T. Katz, MD

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Senator HARKIN. Dr. Katz, thank you very much. That was a very fine statement.

I have just one question for each of you.

Dr. Verduyn, I am, of course, particularly proud that you are here today from the State of Iowa, as I know Senator Cochran is, of Dr. Katz, from Mississippi. Maybe this wasn't just a coincidence here.

We both represent fairly rural states; we heard earlier about head injury occurring in cities. With Jim Brady, the ambulance was there right away to take him out. However small the support systems are out there now, in the cities, what is it like in the rural areas? Both of you have probably had experience with that, not only you from Waterloo, but also from Mississippi.

I just wonder about the long-term care needs of people who live in our smaller towns and communities, what is it like out there. Anything at all?

Dr. VERDUYN. Let me relate to you—again, this is a recent patient—this man was injured 17 years ago, was cared for in Cedar Rapids and then at the University of Iowa, and was sent home three months later.

He and his wife had been married two years. She had one small child at home and had delivered the second one when this man came home. He appeared at my office at the request of a social worker, because he had been in a psychiatric institution after attempting suicide.

This man actually, until a few years ago, had an excellent rehab program. He had initially, after he had improved, worked as a nursing assistant at a local nursing home for about four years. He wasn't really paid, but he had enough pocket money to get around.

After that, he worked for about 12 years at a cabinet shop, where he had to get up in the morning, had to get to work by 7:00, and he would sweep the floor and clean off the counter tops. They did not let him use power tools, although at home, he uses power tools.

When I asked him to show me his hands, he had two fingers missing, but he said that was from before the accident. He did some furniture repair. But he became unhappy at the cabinet shop about four or five years ago, and left, thinking that he could just go out and find another job, which he couldn't.

He now has four children who are teenagers. He complains that the kids always ask his wife and not him. He can't stand the activity that goes on in the house. He is essentially doing nothing.

Now, the rehab program that he actually had has fallen apart. There is a good possibility to develop good programs in rural Iowa. Some of my patients, that have done well, are farmers, children of farmers, who are placed back on the farm and can do the farm labor under supervision. The problem is they will never become the farm operator. They can't do that. But many of them can do farm labor.

I have one young man who was a tractor mechanic. He went back to work. He was injured in August. I saw him in September. He was bleeding, about bled to death. He had not woken up yet. We had a long talk to his wife that we could do the stomach surgery, but that would not save his brain.

She wanted us to go ahead anyway. He started to wake up. He became very restless. We have a large bed that we call a Craig bed. It is essentially a double mattress on the floor. His wife spent the nights with him in the hospital.

He gradually improved. He went home on a pass by Thanksgiving, was discharged by Christmas, and he went back to work January 1st. I said half-days. At the end of the week, I got a call from the owner of the place he worked, and he said, "I can't get the guy out the door, is it okay if he stays?"

This man went back to work as a tractor mechanic full time. Now, this is a small implement dealer who is not in a hurry for production. Sometimes he couldn't remember if he did things right, and had to go back, and he could take that time. He has worked all these years doing quite well.

There are some successes in rural areas. There are a lot of failures because many people essentially become totally isolated. If we are looking at getting people into industry, it is extremely difficult.

I have a number of people that used to work at John Deere, that we can't get back to work, because the employer does not have the time nor the inclination to fit them in.

I do think we need multiple-level programs, multiple-level living arrangements, anywhere from transitional to permanent, that doesn't need to be institutionalized, and if there is anything like an institution, it should be small, three to four people maybe living together under supervision.

We need supportive employment. We need supportive living. Yesterday, someone in a meeting I was at talking about independence. None of us is totally independent. We all are depending on each other. In my office, I am very dependent on the people that work with me, or I couldn't do my work.

We all have a certain form of dependency, and I think we need to realize that. But we would like people to be able to make some of their own decisions.

Senator HARKIN. It would be safe to say, then, that you find there are some success stories in rural America. Perhaps there are some cases that could be made that because of the nature of the small towns and communities, that perhaps there is more of a community care or other alternative like that for an individual.

Dr. VERDUYN. There is some of that, but also I know of many of them that are totally isolated because of their poor behavior. Their families can't go out. They lose all their friends. They are totally on their own, and that can be very difficult. Transportation is not available. They often cannot drive, they have convulsive disorders, and we don't have an organized system, and I think that is the biggest problem.

Senator HARKIN. I think that the one problem that has come through all day, in every panel, is that there is no real organized system that includes prevention, medical services, rehabilitation, job placement, and everything.

Dr. VERDUYN. The greatest problem is the person with the behavior problem, that is unacceptable in society. They often end up in psychiatric institutions, are diagnosed with a psychiatric disease, are treated with psychiatric drugs, and become zombies.

Senator HARKIN. Dr. Katz, earlier I had said that Senator Weicker and I are introducing a bill. I was reading your testimony regarding rehabilitation where you talked about the need for legislation.

As I said, Senator Weicker and I will soon be introducing a bill that we call the Americans with Disabilities Act, which will extend the Civil Rights Act to the handicapped in the areas of employment, public accommodations, fair housing, transportation, and telecommunications.

Again, I want to make the point clear that the Civil Rights Act of 1964 extended those protections to people on the basis of religion, sex, and so forth. Let's say I went to an employer now wanting to get a job, and he looked at my resume and he said, "Oh, you are a Catholic," and I said, "Yes," and he said, "Out the door, I am not hiring Catholics." Well, before the Civil Rights Act, if I went to court, they would say, "What is your cause of action? You don't have a cause of action."

The Civil Rights Act of 1964 opened the courthouse door. Now I can get in. I may have to prove other things, that I am qualified for the job and other things like that, but at least I can get in the door.

If, however, I go now to get a job and the employer looks at me and he says, "Oh, you have epilepsy," he may say, "Well, sorry, I'm not hiring epileptics," even if that epilepsy was caused by a head injury and is now under control. If I go out the door and go down to the courthouse, the judge will say, "Wait a minute, what is your cause of action? You don't have a cause of action." The courthouse door is not even open.

Again, I want to focus on that, and I wanted to ask you your opinions in that area, about extending those protections. Again, I am wondering if that extending this kind of civil rights to handicapped people who don't have them is part of the continuum we talked about, from prevention on through.

Again, I just wanted to get your feelings on it, and your thoughts, because you mentioned some of these things in your testimony.

Dr. KATZ. Well, I think it is a great act, and I think it will help a lot of people. I think that that, by itself, won't do it as well as the education of the community. I think that you have directly under you, to my knowledge—and I am not a politician and I do not keep up with everything—but I think the Department of Vocational Rehabilitation is somehow under this committee. By making them learn, by informing them about brain injury, by making them go to inservices, the they would have to learn, then they could get out into the communities and be a voice, because my voice is getting kind of soft, so I think that that is as important. But pass that bill, yeah, that would be real good. I am sure we can use that for something along the way.

Dr. VERDUYN. May I add a comment? I was involved with a group that were writing this book for vocational rehabilitation in, I think, 1985. The stuff is available. It is not that the materials are not written. They need to be shared and spread around.

Senator HARKIN. I guess I just never looked at this in the context of head trauma before. I have looked at it in other things. We do have Rehabilitation Services Administration under us. In fact,

behind us in the hearing room is the former director of RSA, Justin Dart, who has been a great champion for the disabled.

Thank you both very much.

Senator COCHRAN. Mr. Chairman, could I just ask one question?

Senator HARKIN. Senator Cochran.

Senator COCHRAN. I just wanted to ask one question while Dr. Katz is here. I know that in our State, we have tried to channel more funds and attention to problems in the rehabilitation area, but there does not seem to be the results at the end of the pipeline that we would like to have.

What is your observation about how we could more effectively spend those dollars, and why are the rehabilitation services costing more and more and more every year, and we seem to be getting, not more, but maybe less at the end?

Dr. KATZ. That is a great question, and I have a pretty good answer, I think.

I live in Jackson, Mississippi. I moved down there from Boston, right? And I got a good job and I am making a decent amount of money. Well, as soon as I started doing a very good job there, I get a job offer in New Orleans, one in Miami, one in Atlanta, one in Memphis, and each one, every time I turn down a job, the next one comes back for even more money.

The same thing is true for good therapists, and the same thing is true for good nurses—because there are just so many people that are trained, a very insufficient number, so the price has to keep going up—instead of educating more people, it is cheaper to pay an extra $10,000 or $15,000 and steal someone else's therapist.

So this is reality. I may not be saying it in the most eloquent way, but this is what is going on. So, as this happens, the price obviously goes up. Now you start seeing coma units costing $16,000 to $20,000 a month to keep someone in a coma unit, coma stimulation unit.

Well, I wonder what the reasons for that are because it seem so me that for the type of services that I see being provided in those places, that you could probably—if we did it at the Hyatt-Regency here in Washington, DC, and my room is $98.00, and we had three of four hours of therapy a day, and say the therapist makes a good $20.00 an hour, so you get another $80.00 a day or so, plus food and other things, maybe $250, $300 a day, I don't know, but that still would not come out to as much as—not even half as much as what they are charging now. They are charging $600 a day and more.

I think that that has a lot to do with it. That fuels the cost being driven up that way. And, plain and simple, who should you educate? If you just educate two groups of people, the education system and the vocational rehabilitation system you will save a fortune. Because, I will tell you, right now I see patients back, all the time.

I will see them back in three weeks, five weeks, six weeks. Every time they come it to see me, 45 bucks, 45 bucks every single time, and I am cheap. Forty-five bucks is considered cheap for a physiatrist for an outpatient visit. But I have to see them because the schools are not doing their job, and because vocational rehab isn't doing their job.

One guy I saw 17 times, 17 times just—each time I would see him back, I would call him, he would come back, so that I could

call his vocational. rehab counselor, have you done this yet, have you done this yet?

So if you could have vocational rehab doing their job, which is a whole lot cheaper than the medical system, and the educational system doing their job, which is a whole lot cheaper than the medical system, then you are going to save medical dollars.

Senator COCHRAN. Thank you very much, Doctor.

[Applause.]

Senator HARKIN. I will tell you it is not too often you hear doctors talk like that.

Senator COCHRAN. That is right. Wonderful.

Senator HARKIN. We are very proud of you, both of you, very much.

Senator COCHRAN. It is a terrific hearing. I want to congratulate you again, Mr. Chairman, for convening the hearing and for the selection of the witnesses.

I wish that my schedule had been so I could have been here during the entire hearing, but there are other hearings going on, as you know, in other subjects and other committees, on Appropriations and others, but thank you, and thank all of you who are here helping us better understand these problems and the possible solutions that we have, so we can deal with them more effectively.

Thank you very much.

Senator HARKIN. Thank you, Senator Cochran, for your counsel, for your support on the subcommittee, and for your involvement in this area.

At this point we will include all additional statements submitted for the record.

[Additional material submitted for the record follows:]

STATEMENT OF

MADELEINE C. WILL

ASSISTANT SECRETARY FOR SPECIAL EDUCATION

AND REHABILITATIVE SERVICES

U.S. DEPARTMENT OF EDUCATION

ON

SERVICES TO INDIVIDUALS WITH

TRAMATIC BRAIN INJURY

APRIL 22, 1988

I am pleased to present testimony on the progress being made by the Office of Special Education and Rehabilitative Services (OSERS) to increase the knowledge about and services for individuals with traumatic brain injury (TBI).

In FY 1987 as part of my on-going emphasis on creating new and improved models of service delivery to unserved or underserved populations, I announced a major programmatic initiative on traumatic brain injury. The TBI initiative addressed several important areas of brain injury rehabilitation, including organized planning and program development, new fiscal resources for additional research, development of model comprehensive service delivery demonstrations, coordination of Federal research efforts, and public education and prevention activities. In total, the Department of Education invested approximately $6,500,000 in TBI services and research in FY 1987.

I am happy to report that we have made substantial progress in each of these important areas.

Model TBI Systems Demonstration Projects

Based on a National Institute on Disability and Rehabilitation Research (NIDRR) directed research priority, awards totalling $1.5 million for five new national model systems demonstration projects were made in FY 1987. The models focus on the comprehensive delivery of services from point of injury, through intensive neurological care, comprehensive rehabilitation, psycho-social services and community re-integration and follow-up. A national TBI data base will be established as part of the research and demonstration activity. Projects are located at the following sites:

- Mt. Sinai Medical Center, New York, New York
- Wayne State University Medical Center, Detroit, Michigan
- Medical College of Virginia, Richmond, Virginia
- The Institute for Rehabilitation and Research, Houston, Texas
- Santa Clara Valley Medical Center, San Jose, California

Rehabilitation Research and Training Centers

Funding for four new TBI-focused research and training centers was announced in FY 1987. To date, three awards have been made at the cost of $1,890,000. These university-based research centers will investigate all aspects of brain injury, with a programmatic focus on moderate injury, severe injury and prolonged coma, and community re-integration issues.

Competition for one additional center will be announced in the near future. Those institutions receiving new R&T Center designation include:

- New York University Medical Center (Moderate Injury)
- Medical College of Virginia (Severe Injury)
- State University of New York at Buffalo (Community Re-integration)

National Invitational Research Conference

In November 1987, a national invitational research conference was sponsored by OSERS/NIDRR with the purpose of identifying new directions for future research

in TBI. Approximately one hundred invited participants heard scientific "state of the art" papers and made recommendations for future research priorities. Scientists, clinicians, consumer advocates, and Federal agency representatives participated in each of three programmatic areas: (1) neural recovery and acute care, (2) comprehensive rehabilitation, and (3) community re-integration. A commercial publisher is preparing a book containing the scholarly papers presented during the conference which is scheduled to be available in the Fall of 1988.

Workshop on Nomenclature and Definitions

In March 1988, a workshop was convened by the Medical Sciences Office, NIDRR as an outcome of the November Invitational Conference. One recommendation of the conference was the standardization of terms and definitions for clinical and research uses in TBI. This March workshop brought together the senior staff of the five TBI Model Systems and selected consultants. This group, in developing a national standardized TBI research data base, will establish nomenclature and definitions. It is expected that the results will be disseminated nationally and perhaps internationally.

Field Initiated and Related Research

Since the announcement of the OSERS TBI initiative, there has been a virtual explosion of research interest. This has precipitated the award of several new projects, including eight field initiated projects and two Switzer distinguished fellows in TBI research. Examples of field initiated projects include the study of the effects of drugs on cognitive functioning, the restitution of upper

extremity motor control, and the development of innovative vocational re-integration techniques. The annual cost for the field initiated research projects is $800,000, and cost of the fellowships is $73,000.

In addition, in FY 1987 NIDRR awarded four new Research and Demonstration projects on such aspects of TBI rehabilitation as vocational re-entry, supported employment, and new rehabilitation modalities. NIDRR made a new award in FY 1987 for a TBI Public Awareness project and continued two other projects on brain trauma. The total amount allocated to new and continuation awards in these categories was nearly one million dollars.

Public Education/Prevention Activities

As part of the five Model TBI Systems, public education prevention components have been developed in each project. These public education programs are focused on school age, particularly high school-age, young people who are at greatest risk for TBI. In addition, an innovation project at the New York University Medical Center has developed instructional videotapes for hospital personnel and the lay-public on the consequences of mild brain injury. This videotape series has been distributed to 1600 hospitals in the U.S.

Also, in FY 1987, the National Head Injury Foundation received a NIDRR research award for Project TAP. This project will address the need for education materials in the areas of prevention, early identification, early intervention and access to resources. It will disseminate existing knowledge about head injury to educate head injury survivors, family members, professional caregivers and the general

public on the physical, emotional, and intellectual consequences of TBI, and to help prevent head injuries before they occur.

Rehabilitation Services Administration Initiatives

The Rehabilitation Services Administration (RSA) initiated ten supported employment demonstration projects in FY 1985 and seventeen additional projects in FY 1986 in order to increase the competitive employment opportunities for severely disabled persons, including individuals with TBI. In addition, the Rehabilitation Act Amendments of 1986 established a supported employment formula grant program which will make supported employment services available in each state. In FY 1986, RSA initiated four service demonstration projects to develop service models for individuals with TBI, and six additional projects were funded in FY 1987 which focus on TBI rehabilitation at an overall cost of $1,280,000 in FY 1987. An on-going OSERS initiative in the Centers for Independent Living program is designed to expand services to diverse disability groups, including individuals with TBI.

Interagency Coordinating Committee on TBI

The Interagency Coordinating Committee on TBI was established in response to House Appropriations Committee report language calling for increased coordination among Federal agencies which provide services to individuals with TBI. This Committee is composed of 12 Federal agencies and is chaired by the Director of the National Institute on Neurological, Communicative Disorders, and Stroke in the National Institutes of Health.

The first meeting of this Committee was held on March 21, 1988, and involved the team leader for the TBI initiative in OSERS. The results and concept paper from the OSERS/NIDRR National Invitational Conference will provide a solid foundation for the work of the Committee and assist in the formulation of future plans between the two agencies. Representation from the Interagency Committee on Handicapped Research in the future will insure even greater interagency participation in this Committee.

As you can see, the OSERS initiative in TBI has produced an impressive array of activity in both research and improved services for individuals with TBI. I expect that the outcomes from this initiative will produce substantial benefits in the areas of treatment, rehabilitation, employment, and independent living, and will result in greater opportunities and independence for individuals with TBI.

Wayne State University
College of Engineering

Bioengineering Center
818 W. Hancock
Detroit, Michigan 48202
(313) 577-1344

IPRC
Injury Prevention
Research Center

April 25, 1988

Senate Subcommittee on the Handicapped
113 Hart Senate Office Building
U. S. Senate
Washington, DC 20510

Re: Hearing on Head Injury Rehabilitation

As Director of the Injury Prevention Research Center at Wayne State University, I would like to submit a few comments regarding the recent hearing of the Subcommittee on head injury rehabilitation. As you know, the National Academy of Sciences was commissioned by Congress to look at the total problem of injury in America and has recommended that a concerted effort be made in injury control through research in five major areas. They are epidemiology, prevention, biomechanics, acute care and rehabilitation. The responsibility of funding and overseeing this function was given to the Centers for Disease Control.

Because of the fact that injury, including head injury, is a multi-faceted problem which is extremely costly to society and because it is a problem which requires a coordinated effort by many research disciplines, it is necessary for us to recognize the fact that injury can only be controlled by research in all five areas identified by the National Academy. Although rehabilitation of the head injured patient requires a lot of research, it is also necessary to consider the preventive aspects of head injury, such as research into the methods of protecting riders of cars and cycles from receiving a head injury.

I urge the Subcommittee to charge the CDC with the responsibility to reduce head injuries in this country by a substantial amount during the next decade, using the multi-disciplinary approach outlined by the National Academy of Sciences. Thank you for your attention to this matter.

Yours sincerely,

Albert I. King, Ph.D.
Carr Professor of Engineering

cc: Senator Levin

STATEMENT OF MARC STERN
Marina del Rey, CA

One Victim's View of the Invisible Disability

Today, I find myself caught in a system that has little understanding of my injury. I was a victim, hit on the left front protion of my skull with a metal pipe. My skull was crushed into my brain.

My name is Marc Stern and I am a high functioning permanently brain injured person with a deficit not many acknowledge.

Memory and organizational tasks can be a real problem. In order to compensate for these difficulties, I am requesting what could be called a prosthesis for my brain - - a computer.

The computer and software programs that I have researched and requested will help me overcome many of these problems as well as take advantage of my advanced degree in Art.

With these aids, I will be able to maximize my abilities and minimize my deficits resulting in a richer, more productive life.

I have been well educated, with a Masters of Fine Arts degree from the University of California at Santa Barbara, and Restaurant and Catering Management graduate courses from the U.C.L.A. extension and various associations.

The past two years have been devoted to my quest for recovery and the return to independence, during which time my life savings have vanished, my lifestyle has been put into

serious jeopardy, and I am finding myself once again a victim - - this time a victim of a seemingly uncaring system.

Everything I've mentioned has come about, all because the system fails to recognize brain damage, "the invisible disability," as a disability which can be helped. There seems to be no category of funding or placement for the brain-damaged victim. The high functioning brain-damaged person seems to just fall through the cracks.

So you see, if I had been hit and paralyzed from the waist down, I could have obtained a van with a special lift gate for a sum of $25,000 to $30,000 from the Department of Rehabilitation or Victims of Crime in California. I am requesting the same accommodations for my disability. However, I was told by the State Board of Control that my injury would be "breaking new ground," and it would open the door to new claims, otherwise denied by the State.

My claim was denied.

Testimony submitted by Marc Stern

Marina del Rey, CA

1454 Moberg Road
Mt Vernon, WA 98273
April 2, 1988

The Honorable Senator
United States Senate
Washington, D.C. 20510

Dear Senator

I am most pleased that the Senate Subcommittee on the Handicapped has agreed to conduct a hearing on traumatic head injury on Tuesday, April 12, 1988, from 2:00 to 4:00 pm in the Dirksen Senate Office Building.

During this critical hearing, head injury survivors, family members, and medical experts will present testimony about the number one killer of Americans under the age of 34: traumatic head injury. Current statistics of head injury are staggering: 700,000 head injuries in the United States; 140,000 deaths each year as a result of these traumatic injuries; 50,000 to 70,000 people are permanently disabled as a result of head injuries.

I find these figures especially devastating because one year ago our beautiful 16 year old daughter became one of the permanently disabled as a result of traumatic head injury. In the course of the past year, we have come in contact with dozens of families who are also suffering from the affects of head injury, and we find we all have a common denominator, financial ruin, therefore bringing about every conceivable family problem known to modern man.

In our case, we were an average middle income family with only our house payment and a recently (the month before the accident) aquired payment for the purchase of a 1983 car. Our life was ideal, our 17 year old son was about to graduate and our daughter was preparing for tryouts to be a cheer leader for the 1987-1988 year, her Junior year. Both of our children were very active in sports and Laura our daughter was also into the school debate team and various other activities. Both were average students that gave us very little problem. Both had held summer jobs, our son on a fishing boat in Alaska and Laura in the flower bulb or berry industry here in the Skagit Valley. Both were popular and both were active with our church youth group. Laura had done volunteer work for two years with the mentally handicapped preschool, and as a volunteer at the local hospital. My husband and I had woven our world around our two children and hated to see them grow up so quickly. We found that this closeness has been the only thing that has held our family together this past year.

On Good Friday, April 17, 1987 we watched our daughter leave on a date with a neighbor boy, two hours later we received the phone call every parent is afraid they will receive,the one from the hospital telling us our daughter

was there and they needed our signatures to treat her. What they didn't tell us was that she was in a coma and in critical condition. She was stabilized and transfered to a trauma center 40 miles from our home where she remained in critical condition for over a week and was not removed from the critical care unit for three weeks. Five weeks after the accident she was transfered again to a facility in Seattle, 65 miles from home. Laura remained in a coma for 3 months and was not expected to ever wake up. We were told if she did wake up she would probably never walk or talk if she even had the mental capacity to do either. Laura suffered from defuse injury throughout the brain, with upper brain stem injury and due to a bloodclot in the thalmus gland all her vital functions were impaired.

Our world was smashed to little pieces, our son withdrew from everyone and we entered into a world dominated by our so called legal system. The drivers insurance knew they were at fault, but wanted a settlement with no help in the meantime. Our underinsured policy offered to help, but since Laura was a minor child, guardianship had to be obtained before the money could go through the courts, and our personal health insurance would not help without us signing a 100% payback agreement because they were third party insurance. For me to obtain guardianship it took almost seven full months.

Nine months after the accident, guardianship was granted and by February of this year, insurance money was dumped into the courts and from there into a blocked account accessible only by a court order. In the mean time, I had to quit my job and be with my daughter on a daily basis to make sure she received the care and therapies we were paying for. The rehab facilities available in this area leave a lot to be desired and constant vigilance is a necesity. Our expenses were mounting quickly and between those additional expenses and the loss of my income, our savings were depleted.

We tried every source known to social workers to gain some help financially, but because our daughter is a minor, and my husband still maintains his employment, we are not eligible for any help, period. We were suppose to be able to maintain our home and pay 32 creditors per month on bills of almost $200,000.00. So, we found we had gone from a comfortable middleclass family to a rich poor one.

We brought our daughter home in September both to save money and because we knew she would be happier at home.Since then, financially things have become worse. We had it recommended to us that my husband and I obtain a legal separation so that our daughter and I could go on welfare and therefore be eligible for help. Now, I ask you, does this sound like something that should happen to a healthy family unit in the prosperous United States of America?

Two months ago, under pressure of possible lawsuit, our private health insurance agreed to pay the bills. Now its to late, we are in debt over our heads and we are told the

only money we can get back are the medical payments we made and our milage. To do this we have to pay a lawyer to draw up the papers, ask for a court date, appear in court and ask the judge if he will issue an order to pay anything. This will cost in the neighborhood of around $200.00 each time. The judge can say yes or no. Our legal bills to date are around $7000.00 just to get this far, we have nothing and as the year progresses we won't regain a penny and since life, income tax (we must pay because I had to cash in my IRA), property taxs and insurance never seem to come to an end it looks as though the new used car we make payments on will be the next to go.

The one bright spot in all this is our daughter did wake up in July of last year. At that time she was unable to even move her tongue. She had no instinct and no voluntary control over movements. Due to intensive therapy, she has improved to the point that she returned to school on February 1, 1988 in a wheelchair and unable to talk, for 3 hour long classes daily, and continues therapy in Everett, 32 miles south of our home.She lost none of her mental capacity or memory, so our prayers were answered many times to get her to the point she is now and hopefully she will continue to improve.

I urge you to PLEASE attend this scheduled hearing on Trumatic Head Injury and try in the future to make some adjustment or law that would help families in this situation be able to obtain vital and dependable care for their loved one and to also have some means of financial help with minors that would not draw the need to go on welfare. We desperately need help in this day and age of cars, drugs and alcohol. It seems all we hear about anymore is the epidemic of AIDS. Traumatic Head Injury is known as the SILENT EPIDEMIC for many reasons, and it seems unless a person actually goes through it, head injury is an unknown injury.

Thank you for your time.

Sincerely,

Helen L. Mossington

105 Walnut Avenue
P.O. Box 606
Roxbury, Massachusetts 02119

The Honorable Tom Harkin
Chair, Subcommittee on the Handicapped
United States Senate
Washington, D. C. 20510

Dear Senator Harkin:

This is my second visit to the Capitol. First, I came in 1968 as governor of Massachusetts Girl's State and ambassador to Girl's Nation, guest of the Honorable Senator Edward Kennedy and Senator Edward Brooke.

My concerns encompass what the Senate could potentially do and will ultimately do for handicapped people. Specifically, I am worried about the fate of the survivors of head injury.

It is proper to concentrate efforts on the full rehabilitation of all persons so that each will reap the maximum benefits of his/her talents and abilities, and society, also, will prosper.

Every individual has something to share, be it an idea or a talent. Humanity loses when anyone is unfulfilled or ignored.

Even today, I maintain the ability to read music, write music and verse, and teach them. I can communicate in French and English as well as in Spanish, the last of which I learned post trauma. I am still a licensed physical therapist, able to practice anywhere as such.

We all lose when one plant is uprooted. Let us work towards everyone realizing his/her personal talents and ideas so that all will be happy and fulfilled.

Concernedly yours,

Renae Smith

Senator HARKIN. Again, I want to thank all the witnesses who have come today as well as all of you who are here for the National Head Injury Foundation meetings. I guess you are finishing tomorrow, most of you, and I know that you have been on the Hill lobbying because I have run into some of you going through the corridors.

I know you have been effective, I know you will continue to be effective, and I know the awareness level about this issue is rising. I truly believe that we are on the verge of really doing some things. It is because of all of you, and I just want to thank you all. You are wonderful.

[Applause.]

[Whereupon, at 4:20 p.m., the subcommittee adjourned subject to the call of the Chair.]

86-558 (160)